Is Anybody Listening?

How can young people with Profound and Multiple Learning Difficulties influence their own post-school transition process?

Full Name: Mrs Susan Margaret Sybil Chesworth

College: Hughes Hall

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Declaration: This dissertation is submitted for the degree of Doctor of Education

PREFACE

Declaration

- This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text.

- It is not substantially the same as any I have submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. I further state that no substantial part of my dissertation has already been submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in this Preface and specified in the text.

- It does not exceed the prescribed word limit for the relevant Degree Committee.

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How can young people with Profound and Multiple Learning Difficulties influence their own post-school transition process?

Susan Chesworth – candidate for EdD

ABSTRACT

This research project arose from my experience as the headteacher of a special school. I observed that young people with profound and multiple learning difficulties (PMLD) had no authentic voice in planning their post-school opportunities despite government legislation stating that young people should participate in their own post-school planning. I regard this as a human rights issue.

The prior literature tends to address transition issues for young people with special educational needs (SEN), not the specific issues of young people with PMLD. To have a voice, it is necessary to have a method of communication. The current transition planning process provides little acknowledgement of the degree of communication difficulty experienced by people with PMLD. This project combines a thorough investigation of transition planning processes and the use of innovative communication methods to give young people with PMLD an authentic voice.

Three in-depth case studies are presented of young people with PMLD at various stages of the transition process. An in-depth understanding of the communication of young people with PMLD is developed throughout the project using Intensive Interaction techniques. Alternative models of disability are explored including the development and application of the capability approach when planning with young people with PMLD.

Grounded Theory principles are applied to the collection and analysis of data. The data confirm that current transition documentation is not fit for purpose. The analysis of Intensive Interaction sessions with each individual reveal that the young people can share issues that are important to them. These can become part of the transition process underpinning the statutory requirements. The researcher's reflective journal highlights the importance of self-awareness, sensitivity, creativity and innovation when working with people with PMLD.

The subject and object of the research are developed reflexively in tandem. Innovative methods enable young people to have a voice and to participate in the research process. The outcomes from the project can be applied outside the research, complementing the recommendations and framework proposed by the Rochford Review (2016), which proposes enabling young people with PMLD to have greater autonomy in decisions that affect their lives, and thus empowering young people with PMLD. In this sense, the project is emancipatory.

Dissemination of the project will raise awareness at a local level; the project also has national implications which are important for parents, policy-makers and practitioners. Dissemination will be undertaken in a variety of formats to enable the engagement of a wide and varied audience. For policy-makers and some professionals, the outcomes will be presented through various journal articles and conference presentations. Plans are underway to create a drama workshop designed for parents, practitioners and young people in order to ensure an impact for these stakeholders.

Keywords:
Profound and multiple learning difficulties (PMLD), special school, transition, case study, Intensive Interaction, communication, participation, advocacy

CONTENTS

LIST OF FIGURES

CHAPTER ONE

INTRODUCTION

1.1 Explanation

The introductory section explains my personal rationale for the development of the proposed research project and identifies the need to explore in detail how young people with profound and multiple learning difficulties (PMLD) can contribute to their transition planning from the practitioner perspective. The main focus of the research is the preparation for the post-school transition, with underpinning subsidiary research strands concerning the understanding of young people with PMLD, communication, transition and participation. It is crucial to have a clear understanding of the complex difficulties which young people with PMLD encounter throughout their lives in order to understand their post-school transition process.

The research project considers the complexities of enabling young people with PMLD to exercise their right of self-determination and investigates how young people with PMLD can have a voice and participate in their own post-school planning process. This process of giving the young people a voice is also reflected within the research methodology; in this sense, the subject and the object of the research developed in tandem in a reflexive manner (Kamler & Thomson, 2014). Innovative methods are applied to enable young people to have a voice and participate in the research process. The process develops practice the outcomes of which can be applied to situations outside the research, allowing young people with PMLD the potential for greater autonomy in decisions that affect their lives. It is envisaged that the processes developed in the course of the research may have applications within the transition planning process. The research methodology has the potential to empower young people and can be considered emancipatory (Nind, 2014).

1.2 My Experience as a Practitioner

I have been involved in the post-school Special Educational Needs (SEN) transition planning process for approximately 25 years, in a variety of roles, including as a class teacher, head of the further education department in a special school, deputy and head-teacher of a special school. I was the special education lead in a county-wide, strategic 14–19 curriculum planning initiative from 2004–2006 and am Chair of Governors at a special school. This varied experience has enabled me to appreciate different perspectives on the transition planning process and, in particular, the impact of the difficulty of enabling young people with PMLD to have a voice in their own transition planning process. As a class teacher, I knew the students but felt the system did not enable the students' voice and individuality to be respected and heard. I assumed increased responsibility, hoping I would be able to influence the system to be more attentive and responsive to the particular aspirations of young people with PMLD. However, I found that the wide range of responsibilities carried by leaders and managers within the education system prevents them from giving the necessary attention to making significant changes for young people with PMLD.

1.3 Reflections on my Practitioner Experience

Reflection upon my personal professional experience is an important element of the research process (Glaser & Strauss, 1967). It was my reflections on these experiences that led me to this research project.

I retired from headship with the knowledge that the existing systems were failing to develop the self-advocacy skills of young people with PMLD. Self-advocacy is a means of self-determination (Atkinson & Williams, 1990). I observed that young people with severe learning difficulties (SLD) who are verbal or able to use existing alternative communication systems have a greater chance of being able to self-advocate.

Advocacy should be an integral part of the transition process to enable young people to express their future aspirations. Young people with PMLD have complex and multiple difficulties and there is frequently insufficient time or expertise to provide this group of young people with appropriate adversarial support during the transition process. As a consequence, young people with PMLD have very limited opportunities when they leave

school and are at risk of finding themselves not in a place of their choice as they are seldom able to express that choice.

1.4 The Inter-Relationship of Practitioner Experience and the Research Process

I have extensive practical experience of working with the intricacies and idiosyncratic communication of people with PMLD. I have a thorough knowledge and understanding of the education system as a whole and how it applies to young people with PMLD (ref. 1.2 in this chapter). Throughout my research, I maintain a fine balance between the benefits brought by my previous experience and the potentially restricted response to the emerging data which previous experience may create. I am very clear that my role is that of a researcher with an open mind and endeavour to be responsive to all communication emerging from the young people, other participants in the project and documentary evidence.

1.5 Potential Bias of Previous Experience

Elements from my previous experience bring potential bias to my analysis of the research data (Kamler & Thomson, 2014). I have a strong commitment to human rights, equality of opportunity and inclusivity. When I took up my first position as a class teacher for a group of PMLD students aged 16–19 years, I was shocked to discover that they were still listening to nursery rhymes, yet the mainstream students I had just left were naturally listening to all the current pop music. I immediately set about developing links with mainstream high schools. I was recently asked to advise on education for PMLD young people in a residential group home in a small semi-detached house with very little outside space. The young people seemed isolated from their friends and the local community and I asked myself whether the quality of life for these young people was any better than in the institutions in which they would have lived a few decades previously.

1.6 Impact of Previous Experience

The research project is set in schools with which I have had contact in previous roles. Although my role was now that of a volunteer researcher, I am aware that I observed

through the lens of my previous roles, responsibilities and experiences. These reflections on past experiences bring a practitioner-focused understanding. There is a possibility that these young people are oppressed and I hoped I might be able to emancipate them to some degree through the outcomes of this research. I recognised that my previous experiences have influenced my personal philosophy regarding education, perceptions and attitudes to situations.

1.7 The Research Question

How can young people with PMLD influence their own post-school transition planning process?

Research Question Explanation

The research question emerged from my reflections on my own experience over many years. Young people with PMLD do express preferences, through a twitch of their mouth, a blink of an eye, or a long stare. These communications are often missed unless the young person is with people whom they trust and who know them well. The young person also needs to be in a situation and position in which they feel comfortable. Crucially, these subtle communications can be missed in the transition planning process. The research question is designed to investigate how my observations in a variety of practitioner roles can become part of the transition planning process.

Seeking to address the research question enabled me to combine my own experience with the rigour of academic discipline in order to explore ways in which this group of vulnerable, marginalised young people may be able to advocate for themselves, with appropriate support, through the transition process.

1.8 Challenging Existing Assumptions and Constructs

The project is based on the principle of social justice and explores the social value experienced by young people with PMLD. The constructs and assumptions around this sense of value are at the heart of the research project and the notion of value impinges upon and influences every aspect of the project. Perhaps if young people with PMLD were valued, the project would not be necessary, or at least many of the issues raised by the research process would have been resolved. The value of a person would not be

compromised if their disability were considered within the whole range of human diversity and any additional resources that were needed to enable equal functioning within society were provided as a matter of justice (Terzi, 2008).

Essentially, young people with PMLD are often seen as objects of pity and charity. This may be seen as a consequence of the rise of capitalism following the industrial revolution, which presented the need for an able, mobile workforce who could contribute to the productivity of society. Disabled people did not fit the demands of industrialisation. They were categorised according to their disability and became defined by whether or not they were able to contribute to the industrialised society that they inhabited. Disabled people became segregated; they were given support predominantly in the form of medical assistance, probably in an attempt to alleviate their symptoms or to make them 'better'. This is an honourable aspiration but focusing on these issues can overshadow the need for these young people to be allowed the respect and fulfilment that is the right of all citizens. In the 1950s in Scandinavia, a movement known as Normalisation emerged. It recognised that people with learning disabilities had the right to participate in society in the same way expected of any citizen. This movement was developed by Wolfensburg in the US and had an impact upon the move towards inclusive educational settings over the following decades (Carson, 1992).

The Children and Families Act 2014 3.49 and *The Care Act* 2014 26.1, 26.2, 26.3 and 26.4 heralded the implementation of personal budgets, dependent upon the underpinning principles of a person-centred approach, placing the aspirations of the individual at the centre of all planning activity (Sanderson & Lepkowsky, 2014). From the evidence of young people with PMLD with whom I work, the cost of medical and care needs are paid from personal budgets before the right to the development of competences is addressed. This practice is at odds with current disability and equality theory based upon the competencies and functioning identified by Amartya Sen (Terzi, 2008).

A key element of the research is the investigation of communication opportunities for young people with PMLD. I hope that the tools that have been used will enable a shift in the public perception of the contribution to society that young people with PMLD can

make. For example, the communicative silence which can exist between a young person with PMLD and a communication partner (Mercieca, 2013) enables the sharing of a common reflective space, a sense of deep knowing between the two people and a time to think about how best to communicate with each other. I have experienced this myself and colleagues have endorsed this form of communication.

It may be of value to learn alternative reflective communication that acknowledges and respects the need for quiet and silence amidst our vocal, outcome-driven communications with each other, truly valuing the competences that everyone has to contribute to an inclusive community.

1.9 Understanding Young People with PMLD

When reading this research report, it is vital to appreciate the degree of difficulties experienced by all young people with PMLD. Young people with PMLD have the most severe and most profound learning difficulties (Simmons & Watson, 2014) and may have physical, sensory and behavioural difficulties (Pagliano, 1999) which may be chronic and lifelong (Male, 2015). Despite these difficulties, the people who work with these young people and know them well can give many examples of their abilities (Lacey, 1998). When planning future opportunities for young people with PMLD, Male (2015) suggests that it is important to focus upon their quality of life, what they can do and what they would like to do.

1.10 Potential Tensions in The Emerging Data

Throughout the project, I asked searching questions of myself and the emerging data. This is particularly important at the analysis stage. There are inherent tensions when working with young people with PMLD, including the tension between government rhetoric and the resources available to implement policy. Government policy can be a reflection of societal constructs of disability (see Literature Review 2.4). As a society, we demonstrate confusion as to how to treat people with disabilities, particularly young people with PMLD. I have experienced being in a café with students with PMLD when people have vacated the nearby tables yet given me money to buy the 'poor young people' a drink. There is a tension between caring for these young people yet giving them the respect and autonomy to be included and make decisions for themselves.

1.11 Ethical Issues

Working with such vulnerable young people presents enormous ethical challenges that could discourage researchers from engaging in research with this particular group, thus increasing their isolation. Yet the possibility exists that I could be seen as exploiting the young people, making them the focus of the research for my own gain (Miles, Huberman & Saldana, 2014). This interpretation is possible because there are significant challenges concerning consent to participate and ownership of the research for young people with PMLD. The subjects are vulnerable young people and it is vital to protect their privacy, to maintain confidentiality and to obtain their approval or consent (Yin, 2014).

In order to overcome the ethical issues, innovative approaches are required. There is a risk, however, that innovative approaches may not stand up to academic scrutiny in the traditional sense. I have been challenged by fellow research students to explain how the research would be validated in the absence of comparative data within the project. I ran a pilot project that provided insight into the depth of exploration that is possible with young people with PMLD. The depth and richness of the data that provides validity are developed throughout the research project. The voices of young people with PMLD must be recognised with parity of esteem within the rigours of academic scrutiny, with respect for and acknowledgement of all the ethical issues. The importance of equal value for all subjects and participants in the research project is promoted to enable young people with PMLD, or whatever other label may be applied to identify this group of young people, to have control of their own lives (Oliver, 1994).

1.12 Summary

The focus of my research includes some of the most vulnerable young people in society. They all have significant cognitive impairments and other disabilities and this must be remembered throughout the research process, whatever the circumstances.

The research design is intended to provide a journey of discovery into unchartered territory within a combination of previously used practices and methodologies.

Rhetoric and government legislation are confusing but profess to endorse the participation and inclusion of this group of young people. I intend to explore the possibilities of making the rhetoric a reality for young people with PMLD.

1.13 STRUCTURE OF THESIS

Glossary

A glossary of terms specifically relating to special needs education is included to assist the reader's understanding of specialist vocabulary. In the text, a word followed by G and a number will be found in the glossary beside the number indicated in the text, for example (G21).

Blue Insert Boxes and Diagrams

Blue insert boxes at the end of Chapter Three – Methodology and throughout Chapter Four – Findings contain examples of points that emerged from the data. Diagrams throughout the text support points discussed in the text at that particular point.

The First Three Chapters

The first three chapters set out the context and the plan of the research project. Chapter One is the Introduction and Chapter Two presents the Literature Review, which sets the research project within the context of previous and current work in this particular field and associated fields. It identifies the particular gap that this research project will attempt to address. Chapter Three – Methodology sets out the methodological plan for the project.

The Middle Chapter

Chapter Four – Findings, is the heart of the thesis. It includes the presentation and analysis of three individual case studies. It is a long chapter that can be read as a whole or as four separate units: documentary evidence and the three individual case studies. The individual case studies present and analyse data from interactive sessions, discussions with significant people in the life of each young person. This chapter also contains a presentation and analysis of extracts from the reflective journal kept throughout the project.

Final Chapters

The final two chapters, the Discussion and Conclusion, draw upon the data and analysis presented in previous chapters and look ahead to future potential developments.

CHAPTER TWO

LITERATURE REVIEW

RATIONALE FOR RESEARCH QUESTION WITH REFERENCE TO LITERATURE IN ASSOCIATED FIELDS

2.1 Introductory Comments

The focus of the research is the involvement of young people with PMLD in their own preparation for post-school transition. For further detail of PMLD please see 2.4 and for Transition please see 2.7. I explore a number of underpinning subsidiary research strands through a review of the literature, including literature relating to SEN in general; Severe Learning Difficulty (SLD) and in particular PMLD; communication in general, communication relating to SEN, and communication specifically with young people with PMLD. Literature relating to transition in general and, more specifically, to young people with SEN and PMLD is also included. Advocacy is an important thread running throughout the research, and literature related to advocacy with specific reference to SEN and PMLD is reviewed.

The substantive review of the literature comprises texts from 1970 to the present. The majority of the material reviewed is from the United Kingdom and the United States, but material from several other countries including India, Brazil, Australia and several European countries is also included. The timespan of the literature review, from 1970 to the present coincides with my professional career in education. The *1970 Education Act (Mental Handicap*) was a landmark for young people with PMLD who were for the first time included in the education system. Their education became the responsibility of local education authorities. This provides me with a context within which I can locate the literature as it develops through this period. In this sense, a literature review is like a journey from one point to another: it is an incremental development of knowledge, opinion and the interpretation of specific phenomena.

My research focus derives from my experience and observations in a variety of roles in special schools ranging from class teacher to headteacher. Throughout my work in special education, I was conscious that young people with PMLD, despite government legislation, did not have the opportunity to influence their own post-school transition planning. Through a review of a wide range of associated literature, I was looking for the elaboration of my observations as a practitioner. I wanted to set my work within an academic context and understand the background to the current situation and the socio-political contexts which have influenced the development of attitudes and policies towards young people with PMLD.

It is important to reflect upon the context in which any piece is written. A study relating to disabilities written in the 1920s or 1930s would have been written within the socio-political context of the eugenics movement which proposed that the population could be improved by inhibiting reproduction within certain groups. Following the *1944 Education Act*, local education authorities were expected to identify children from the age of two who would benefit from special education provision. Nevertheless, some children were deemed ineducable. Following the Second World War, a mother of a child who was deemed ineducable founded the National Association for Parents of Backward Children and, in 1952, The Spastics Society was formed. Following the impact of the Second World War, it is possible to identify a slowly changing attitude to children previously deemed ineducable. The *1959 Education Act* stated that such children were not ineducable but were unsuitable for school. This group of children became the responsibility of local health authorities who developed training centres for them. These proved popular, and training programmes were developed for staff, marking the start of specific training for teachers of this group of children. Throughout the 1960s, demands grew for children with PMLD to have the same right to education as all other children (Segal, 1974). In 1970, *The Education Act (Mental Handicap)* was passed, finally including children with learning difficulties in the education system. All children thus became the responsibility of the local education authority and, from this landmark – the education and inclusion of pupils with learning difficulties – a pedagogy has developed and is still developing.

A review of the literature associated with SEN, and PMLD in particular, is vital to broaden the depth and range of my understanding of these topics. I intend to corroborate and challenge my practitioner experience with academic research and thought in the field.

It is equally important to identify the gaps in the academic research specifically related to young people with PMLD influencing their post-school transition planning. This justifies the need for the current research project. I realise that innovative approaches need to be applied to the research because of the young people's profound difficulties. Within the literature, I noted examples of innovative qualitative research approaches. This led to literature relating to social and political policy, particularly those studies focused on the empowerment of marginalised groups within society (Sen, 2012; Tertzi, 2008).

2.2 The Approach to the Literature Review

Whatever literature an individual reads, the reader brings to that literature their own personal experiences, attitudes and values which influence the objectivity with which the reader engages with the text.

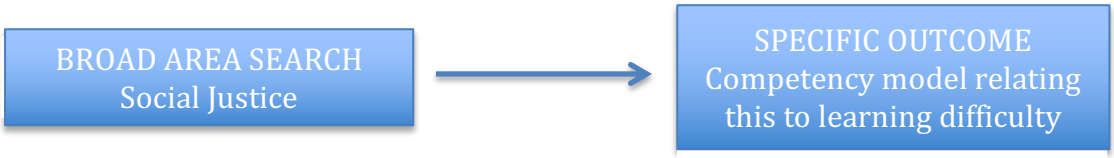
At the planning stage of my research, I read texts and articles reflecting a broad range of perspectives regarding transition. This included transitions throughout the education system, from nursery through to leaving full-time education, and not just related to pupils with SEN. I referred to texts on a broad range of issues relating to communication, including the development of communication in infancy and early childhood, effective communication, communication difficulties and alternative forms of communication including non-verbal communication. Texts regarding SEN/PMLD were an important part of my search and included texts involved with social and educational inclusion. I also read texts and government documents regarding the development of SEN/PMLD in educational settings and broader society. Advocacy is an important strand of the research project and I, therefore, referred to texts involving advocacy groups such as People First as well as texts regarding person-centred planning and support circles for people with disabilities. I reviewed a broad range of texts about disability which provided various definitions of disability, perceptions of disability and

disability rights and insights into how attitudes and perceptions have changed over time. Issues relating to equality included age, race and gender, in particular, to provide contextual information.

I read a wide range of texts regarding research methods, particularly those relating to qualitative research methods, including action research, ethnography, case studies and grounded theory. Other supporting literature subjects included social, political and economic influences, and the historical perspective relating to the research focus. The literature review includes material that has stimulated new ideas and approaches and influenced the direction of my research in innovative ways.

This wide-ranging approach not only provided general background to my research but also led to unexpected discoveries of relevant material (see Figure 2.1).

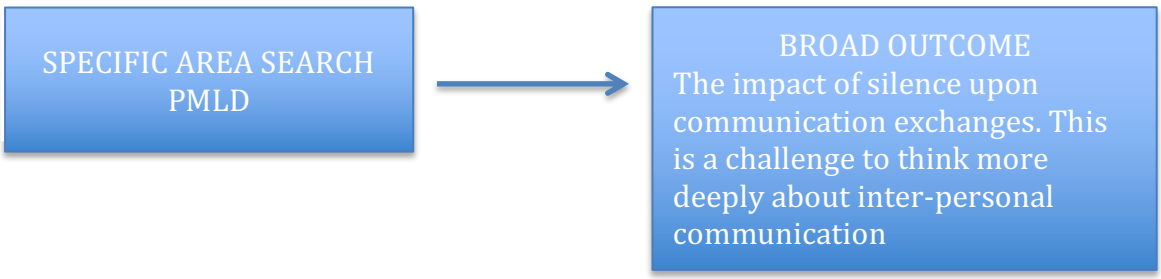
Figure 2.1 Literature Search Broad Approach



For example, through the broad literature search relating to social justice, I discovered a theory of competency and functioning that was originally based on economic theory related to enabling people living in poverty to lead fulfilling lives. I pursued this and discovered a capability approach had been developed to enable people with disabilities (Nussbaum, 2011; Terzi, 2008).

Through a process of following leads within the references of these texts, I identified more specific material related to my research focus. Through this gradual process of refinement, I identified texts that developed my thoughts about my research. The review of more focused relevant texts led to broad outcomes that challenged and provided breadth to my existing thinking on particular subjects (see Figure 2.2).

Figure 2.2 Literature Search Specific Approach



Through my reading about PMLD, I encountered a text that introduced the concept of the use of silence in interviews (Mercieca, 2013). The author was working with students with PMLD and wrote about the silence that can ensue between a person with PMLD and another person. This silence can be uncomfortable, yet, if treated with respect the person with PMLD will eventually respond. Often verbal communicators rush in with words to fill the gap of silence, without respecting the silence or allowing other communication to emerge. This was something I had experienced but had not thought about in this particular way; thus, my reading provided greater depth to my approach to the research project.

I have used a wide range of material, some having more influence than others, including books, journal articles, research articles and some material from the Internet. Literature that relates to the particular focus of this research from other parts of the world is limited. I used background material to set the political, social, educational and historical context of my research and for general investigation around the subject in broad terms. While this was an important part of my research, it had no significant impact and is therefore not included in my main literature review as shown in Figure 2.3.

Substantive and influential material is important for endorsing and developing my existing knowledge. The scrutiny of this material has enabled me to locate my research within existing work in the field and to identify the gap in existing knowledge that my research addresses.

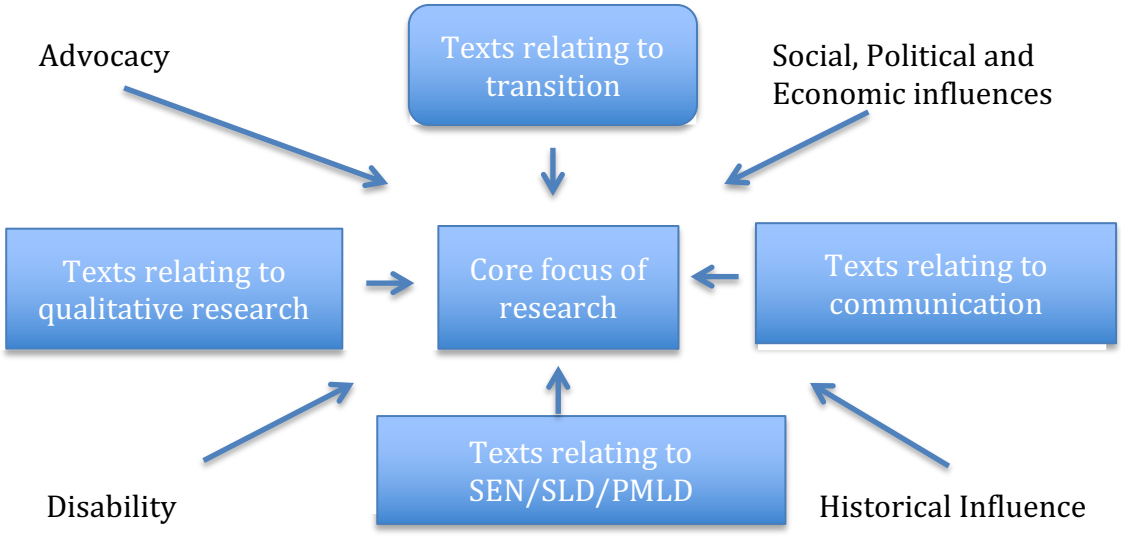
Figure 2.3 Use of Material in Relation to the Research Topic

The literature straddles three genres and professional contexts: health, education and social care. Each genre has its own particular bias and value system. The period of this review includes a change in attitudes towards human rights and equality of opportunity, with a rise in personal aspiration and a huge impact of electronic communication across the globe.

2.3 The Inter-Relationship of the Literature Texts

Figure 2.4 shows the relationships between the texts and their importance to the project.

Figure 2.4 Literature Texts Inter-Relations



Those texts closest to the core research focus are the key texts and those on the perimeter are supporting texts. I assumed when I began the literature review that the key texts would be the most influential; however, the supporting texts challenged and influenced my perception of the research project. Justice and Equality in Education (Terzi, 2008) presented innovative ideas about social justice within the field of special education with reference to the work of Amartya Sen and his proposal that equality should be defined in terms of functioning and capabilities. This presented an alternative way of considering the lives of people with PMLD. I then read further work of Sen, developing his ideas on capabilities (Sen, 2017). Thus, my ideas developed in the course of exploring the literature, often leading me to texts that were more influential upon the research project than those I would have expected at the outset of the exploration.

I approached what I considered to be an influential text about transition for young people with SEN (Dee, 2006) but found that it was of limited use for my particular project. It presented a thorough report and analysis of the transition process as experienced by key stakeholders at the time of publication in 2006, based on twelve individual case studies. While all the young people had a range of problems, including visual difficulties, emotional difficulties, physical difficulties and moderate learning difficulties, none had the complex degree of difficulties of the young people who were the focus of my research. Only one case study, Maria, had a level of difficulty approaching that experienced by the young people I intended to work with. The study identified that Maria's aspirations were unknown and that her mother made decisions that she considered were in Maria's best interest (Dee, 2006). This text confirmed what I already knew from my professional practice; it did not develop my thinking. It confirmed that there was a potential gap in the research regarding young people with PMLD.

2.4 Understanding Young People with PMLD

Young people with PMLD have been identified as a particular group for many years, as demonstrated by various Acts of Parliament. Following the Second World War, a group of pupils was identified as having disabilities deemed to be so significant that they were

considered ineducable (*Education Act 1944* 34:4–5, 38.3). This group included young people would now be considered to have PMLD. Later they were redefined as being unable to participate in sustained education but were provided for in training centres established by health authorities (*Mental Health Act 1959* 12.1). In a spirit of optimism, there was a growing recognition that a range of services, including education, should enable each child to reach their potential (Segal, 1974). This was a significant development in reducing the impact of a fixed intelligence approach that had been a feature of the eugenics movement (Lowe, 1998). This provided the stimulus to develop a pedagogy for children and young people who had previously been considered ineducable.

The Education *Act 1970 (Handicapped Children*) identified pupils with a very severe physical handicap or severe sensory defects in hearing, vision or speech (Segal, 345). Following the Act, children with cognitive difficulties, including pupils with PMLD, were deemed to benefit from education. The education department assumed responsibility for the education of all children of statutory education age (*Education Act 1970 1(i)(a)*).

The *Education Act 1981* paid particular attention to pupils with SEN and how they should be catered for within the education system. This had significant influence and identified procedures such as the development of statements of special educational needs, designed to ensure that all pupils had provision appropriate to their needs, and applied to pupils with PMLD.

In 1988, the *Education Act* introduced the National Curriculum, stating that all pupils were entitled to a broad and balanced curriculum. However, the Act contained no provision as to how this broad and balanced curriculum should be delivered for pupils with learning difficulties (Copeland, 1991). The notional inclusion of pupils with PMLD in a national broad and balanced curriculum eventually stimulated further development in pedagogy and, in 2001, the Quality and Curriculum Authority (QCA) published the P levels that defined levels of attainment for pupils working below level 1 in the national curriculum. This development had a considerable impact on the education of pupils with PMLD. Pupils followed a broad curriculum and were regularly assessed against the P level attainment levels. Subsequent government legislation considered those pupils

working below the national expectation. This includes the *Rochford Review 2016* that makes recommendations for pupils with PMLD and sits alongside current education legislation.

Despite the evolving legislation, the definition of PMLD has remained essentially the same as illustrated by the following descriptions: young people with PMLD have very severe physical and sensory defects (Segal, 1974); they may have physical, sensory and behavioural difficulties, demonstrating multiple challenges (Pagliano, 1999). Young people with PMLD have the most severe and profound learning difficulties (Simmons &Watson, 2014) and experience difficulties that are chronic and lifelong (Male, 2015). Over the past four decades, the essential identified characteristics of a young person with PMLD remain substantially unchanged.

People whom we would currently describe as having PMLD were previously described as having 'defects', as stated in *The Mental Deficiency Act 1913*. 'Defect' implies that a person is essentially flawed and the word has gradually been replaced by other terms. In the 1950s, the term 'handicapped' began to be used. This was followed by 'disability' in the 1970s and, currently, young people with PMLD are considered to have 'difficulties'. The latter three terms – handicap, disability and difficulty – subtly develop the notion that, with appropriate support and changes to their environment, an individual's difficulties can be minimised.

Various attempts have been made to label and categorise people whom we would now consider to have PMLD. As mentioned in the previous paragraph, following The *Mental Deficiency Act* of 1913, such people were described as having defects. The complexity of these 'defects' was not identified but it can be assumed that people with PMLD were considered to be 'defective.' Since then, there has been a gradual process of refinement of the definition of people with PMLD. Following the 1944 *Education Act*, as mentioned in paragraph 2.4, many young people were considered 'ineducable', 'subnormal' or 'severely subnormal', all terms implying a judgement according to normative criteria. Following the *Mental Health Act 1959*, young people with cognitive impairments were included in the provision of education, leading to a categorisation of people with cognitive impairments. Following the 1970 *Education Act (Mental Handicap)*, young

people were designated to have mild, moderate or severe SEN and were provided for in schools focusing on a particular designated category. The 1970 Act includes in its title the word 'handicap'. Handicap indicates a restriction in ability or function and is a generic term covering many forms of limitation. Gradually, the significance of cognitive difficulties was recognised and, in the *Mental Health Act 2007*, learning disabilities and severe learning disabilities were officially recognised. The terms 'disability' and 'difficulty' are often used interchangeably.

Simmons and Watson (2014) provide an account of the development and influences upon the education of young people with PMLD. Behaviourist approaches were very influential in the early development of pedagogy for young people with PMLD and were used to effect a wide variety of behavioural changes and responses. Gradually, cognitivism began to gain influence when teachers began to consider the cognitive activity occurring behind the observable behaviour and this led to the development of other responsive approaches, including intensive interaction and responsive environments (Simmons & Watson, 2014). I was particularly interested in the explanation of phenomenology in relation to young people with PMLD, a notion that gives credence to the different experiences of agency and embodiment and the relationship between thought and communication (Merleau-Ponty, 1962), challenging us to see behaviour and potential agency in a different, more open-minded way. This notion was further developed by the work of Mercieca (2013), who identified the opportunities created by people with PMLD when we are challenged to reconsider our communication and to consider the effect of the silence that people with PMLD create within communication. This idea can be developed to explore the lived experiences of young people with PMLD, attributing them equal value but acknowledging their difference without a demand for observable behaviours (Simmons & Watson, 2014). This resonated with the way I intended to develop my research project.

Young people with PMLD are a small marginalised group. Their complex disabilities make it difficult for them to participate in many activities within society, creating a situation where in many respects young people with PMLD are unknown (see also section 2.7) and are little valued within society. Kittay (2019) draws attention to this situation as a philosopher and the mother of an adult daughter with PMLD; she

highlights the dilemma that, in order to value a person, you need to know them but, unless you have very direct contact with a young person with PMLD, you are unlikely to have the opportunity to get to know them. This situation reinforces the lack of value attributed to these young people. It has been recognised for many years that, despite the difficulties encountered by young people with PMLD, those who work with them and know them well can give many examples of their individual capabilities (Lacey & Ouvry, 1998).

Value and quality of life (Johnson & Walmsley, 2010) are based on notions of normality, yet our own sense of normality depends upon spending our life with others who value and love us (Kittay, 2019). The notion of normality is at the heart of medical models of disability which emphasise corrective action to change an individual, in order to make that person like other people. In the 1960s, children born with disabilities as a consequence of thalidomide were fitted with often painful prosthetic limbs so that they could appear the same as other children. The situational dilemma for young people with PMLD is still deeper. Kittay (2019) challenges the understanding of a good life, seeing it not about accomplishments but what one person can bring to the life of another. This sentiment is echoed by Mercieca (2012) who identifies the gift of silent reflection that young people with PMLD bring to the lives of those around them.

Kittay (2019) draws attention to the notion that the problem lies not in the impairment but in the response of others to that impairment. This links with the social model of disability (Oliver, 1992) in which disability is the result of insufficient resources to enable a person to function with an impairment and can be countered by, for example, increased mobility options for disabled people through public transport with disabled access facilities.

Within the literature relating to disability, there is much discussion regarding independence and the rights of people with disabilities. Even with modifications to the environment such as those heralded by the social model (Oliver, 1992), young people with PMLD are dependent on the care of others to access facilities and opportunities (Kittay, 2019). It is difficult for these young people to develop independence in the sense of doing things for themselves but this should not prevent them from being self-

sufficient. Self-sufficient in this context would mean that the young person had confidence in their own abilities and worth, requiring them to develop skills of self - determination (Kittay, 2019). The development and sustainment of this self-sufficiency are crucial in the relationships experienced by young people with PMLD but, to achieve it, greater understanding is needed of a real quality of life for young people with PMLD, as discussed in Section 2.9.

The relationship between young people with PMLD and those who care for them is crucial to the development of their sense of self and self -sufficiency. Kittay (2019) argues that the relationship should be one of inter-dependency, where each helps the other to flourish. When there is a genuine closeness with a young person with PMLD, it is important to consider as part of the relationship the sadness and negative impact of the disabilities and the impact these have on the non-disabled person's emotions (Firth, Berry & Irvine, 2010).

The acknowledgement that young people with PMLD have agency takes further the notion that they have individual abilities. When young people with PMLD have agency over other people, they are contributing to the development of the other person in an equal relationship. They can make other people stop and think differently, as noted by Mercieca (2013) who proposes spending time engaging with young people with PMLD, enjoying the space that they offer and invite you into. This can provide an opportunity to respond to the invitation to stop and look at life in an alternative way, enjoying the creativity of this space.

The field of literature relating to young people with PMLD is small but contains work that has been written by people who know young people with PMLD in great depth; for example, Kittay's contribution is invaluable because of the intimate knowledge she can share as the mother of an adult with PMLD combined with her academic credence as a philosopher Kittay (2019) and this small field is enriched by the contributions of Terzi (2008) and Mercieca (2013). There is a developing understanding and appreciation of the contribution made by young people with PMLD, and their sense of belonging to whatever community they are part of is identified by Nind and Strnadova (2020).

Although young people with PMLD can be recognised by people who know and work with them, confusion remains as to whom precisely the term PLMD applies. Many people agree with the definition proposed by Ware (2004) that a person with PMLD has one or more of the following: significant motor impairments, significant sensory impairments, complex health care needs or dependence on technology. Jacobs, MacMahon and Quayle (2018), however, identify people with PMLD as having non-verbal or very rudimentary communication, being in need of substantial supervision and support, and reliant upon others to make life-changing decisions. In the following sections, specific aspects of PMLD and how they affect lives will be discussed in more detail. These include communication, intensive interaction, transition, advocacy and social justice.

2.5 Communication

Much of the literature about the development of communication for young people with PMLD echoes the sequence of developments described in Section 2.4. The behaviourist and cognitive approaches referred to by Simmons and Watson (2014) began to be challenged following in-depth studies of the communication development of non-disabled babies and young children, particularly the interaction between mothers and their babies (Snow, 1977). The recognition that communication can only be taught and understood through interaction with others (Goldbart & Coupe O'Kane, 1988) was crucial and led to the development of more interactive approaches to communication development for young people with PMLD. It must, however, be acknowledged that behaviourist approaches using positive reinforcement to learn signs, symbols (G52), objects of reference (G30) and picture exchange systems (PECS), and cognitive developmental approaches including psycholinguistic and sociolinguistic approaches continued to have considerable influence in the teaching of communication in schools (Goldbart & Coupe O'Kane, 1998).

Language and communication develop within a context. If the environment is responsive to the young person's actions, then the young person is more likely to be responsive to the actions of others and to recognise that they are part of a communication partnership. Young people with PMLD have characteristics such as unusual facial expressions, a tendency to dribble or spasticity. Ware (1996) suggests

that these attributes can make it difficult and potentially unrewarding for others to communicate with them.

Many alternative methods of communication are introduced to children with PMLD aimed at teaching the child that a response is expected of them (Ware 1996). Corke (2012) argues that other aspects of communication development are equally important, such as the free-flowing attunement between people that encompasses tone of voice, warmth sensitivity, touch and facial expression. Language and communication development occur within a social context alongside other aspects of human development.

Goldbart and Coupe O'Kane (1998) contend that those who work with young people with PMLD can interpret pre-intentional communication and reinforce this with meaning. Through a gradual process of shaping behaviour with meaning, the young person will develop intentional communication providing them with some degree of agency over their immediate environment.

The above provides an overview of the main aspects of potential communication development for and with a young person with PMLD. Intensive interaction provides a means of total communication that includes many of the aspects previously discussed (Hewett, Firth, Barber & Harrison, 2012). The identification and development of my understanding of intensive interaction have provided me with a potential method of communication with young people with PMLD, and a method for developing the case studies within this research project. The application of intensive interaction opens a potential window of communication for young people through the transition process, depending upon the outcomes of my research.

2.6 Intensive Interaction

Intensive Interaction developed from work carried out at Harperbury School in the 1980s. The school was trying to develop alternative methods to the behaviour modification techniques commonly applied when working with young people with PMLD. Led by the headteacher and a clinical psychologist, the team of teachers applied methods based upon the interaction between mothers and babies (Hewett et al., 2012).

Intensive Interaction has developed as a holistic approach to communication with young people with PMLD. Essentially it is between two people – a skilled communicator and a less skilled communicator – sharing personal space and proximity. It promotes social interactivity for people who find interaction difficult to understand and aims to establish a sense of mutual pleasure and intentionality within a communication exchange that is not task-orientated (Firth et al., 2010). The role of the skilled communicator is to respond to the less skilled communicator in a facilitative manner (Barber, 2007). The approach seeks a connection with a person who is difficult to reach. Kellett (2003) conducted a systematic evaluation of the Intensive Interaction approach and recommended its development. Kellett (2005) conducted further detailed work with young people with PMLD and described the benefits of Intensive Interaction in developing social interaction. A young person with PMLD may not be used to communicating, and especially not used to being acknowledged as the initiator of communication. To begin an interactive relationship may require the skilled communicator simply to copy the sounds that the young person makes to mirror their breathing pattern. Following the lead of the young person with PMLD, the skilled communicator becomes involved in the sensory world of the young person with PMLD.

There is a developing literature associated with Intensive Interaction, examining its use in a variety of settings, including schools (Watson & Fisher, 1997) and adult care settings (Samuel, Nind, Volans & Scriven, 2008). The impact of Intensive Interaction on the emotional wellbeing of people with PMLD has also been investigated (Nind, 2009). All these studies identify a positive impact of Intensive Interaction and highlight the need for further use and development of Intensive Interaction methods and concurrent evaluation.

Firth (2009) recognises that practitioners and researchers need to develop an understanding and definition of Intensive Interaction as it is complex and multi-faceted and is used with a wide variety of people. This makes it very difficult to conduct methodologically sound research into its effectiveness (Hutchinson & Bodicoal, 2015). Firth (2009) identifies two process models of Intensive Interaction:

- a social inclusion model that focuses on shared understanding, connecting and language;

- a developmental process model that focuses primarily on the development of communication and skill acquisition.

Firth believes that these two models are complementary. Within Intensive Interaction, skill development is similar to scaffolding and the zone of proximal development identified by Vygotsky.

There have been audits of Intensive Interaction services in South England NHS Trust (July 2015) and Brighton (2015) (Baker, 2015). These studies endorse the positive impact of Intensive Interaction but highlight the need for on-going support and training for staff in order to maintain the effectiveness of the interactive methods. The commitment to support and training depends upon the commitment of managers and health authorities. Although practitioners working with people with PMLD recognise the benefits of Intensive Interaction, managers with less contact with people with PMLD may not see support and training as being a high priority among the many other demands they face, presenting a conundrum.

For people with PMLD, Intensive Interaction can affect their social interaction, empowering them and enhancing their ability to open up and interact with people in wider situations. In order for people with PMLD to interact, it is crucial that they have opportunities to do so (Vorhaus, 2015). The sense of value that Intensive Interaction promotes has a positive impact on the mental health of people with PMLD, who are often forced to respond like children because of a lack of understanding and a power imbalance in their relationships. Intensive Interaction introduces an atmosphere of equality and mutual respect (Firth et al., 2010). Studies supporting enhanced social engagement for people with PMLD are more prevalent for adults than for young people in education (Zeedyk, Caudwell & Davies, 2009), possibly as a consequence of the current pressures of the school curriculum and the drive to achieve observable, quick outcomes.

Often, in a school setting, the young person is expected to attempt the virtually impossible challenge of participating in the world of skilled communicators (Barber, 2007) which dominates the transition process. Intensive Interaction offers an alternative communicative approach that may provide the young person with a means

to express him/herself throughout the transition process in a manner that is meaningful for that young person. Evidence from the use of Intensive Interaction in adult settings further endorses its use as a tool to enable a young person to express themselves and to contribute in a manner that they feel comfortable with. There is evidence that this may continue in post-school settings to enable further social interaction.

2.7 Transition

Transitions form part of life for everyone; they involve physical changes and maturation. Within the scope of this research project, this process of transition will focus on young people with PMLD on the threshold of adult life, reaching the end of school (Jacobs et al., 2018). The transitions for young people with learning difficulties are the same as for other young people.

The education system has particular transitions, for example from primary to secondary school, and leaving school for further education or training and these transitions are, in some respects, different for young people with PMLD, who have often been at the same school from nursery through to the end of Key Stage 4. The school staff is familiar with each young person's highly individual support needs. Young people are more dependent upon family and professionals to support them and, indeed, are dependent upon others for all their care needs, feeding and personal care. Because of their significant communication problems (Stranadova & Evans, 2013), it is often virtually impossible for them to make themselves understood to people who do not understand their idiosyncratic ways of communicating.

The post-school transition process brings a sense of a change in belonging. Jacobs et al. (2018) identified the sense of loss that young people with PMLD and their families experience at this time: for many years a young person with PMLD and their family will have felt they belonged to the school community. It is difficult to know what this sense of belonging means for a young person with PMLD (Strnadova & Nind, 2020) and this area needs further exploration but it should be acknowledged. If all the detailed information available is passed to the new environment and the new environment pays detailed attention, then transition can be a very positive experience for a young person with PMLD. The right people must have access to the detailed transition information.

The attitudes and expectations of different systems and people involved within the transition process may vary and this can create problems for the transition of young people with PMLD who are dependent upon others to transfer information on their behalf (Strnadova & Cummings, 2014). This includes personal information about their feeding and personal care requirements in addition to their interests and aspirations.

The transition planning process for young people with SEN is laid down through government legislation in the first *SEN Code of Practice* (DES 1994). There have been modifications but, essentially, the guidance for transition planning for young people with SEN has remained the same. The government document *Removing Barriers to Achievement* (DES 2004: 3.40) acknowledges that procedures in the *Code of Practice* were not always followed. The guidance states throughout that young people should be involved in their own transition planning but recent, significant evidence indicates that only in a few exemplary cases have young people with SEN been involved in their transition planning (Draper Rodriguez, Cumming & Strnadova, 2017). Despite this acknowledgement, the current *Code of Practice* (DoE 2015) remains unchanged, with little evidence of quality assurance or monitoring. From Year 9, young people with SEN and their parents should attend an annual multi-professional transition-planning meeting so that all those involved with the young person can come together to discuss the opportunities available and support needed as the young person prepares to leave school. The young person should be involved in the planning and decision-making process (DES, 1994).

Although it is acknowledged that the voice of the young person in the decision-making process can have a significant impact (Dee, 2006), young people with PMLD are least likely to have their views and choices heard and are frequently excluded from transition planning meetings (Jacobs et al., 2018). Mansell and Beadle-Brown (2012) suggest that everyone should have the opportunity to make simple choices within their daily life. This will provide them with the necessary skills to demonstrate choice in the transition process.

Young people with PMLD have idiosyncratic methods of communication that need to be understood in order that they can participate (Porter & Lacey, 2005) and influence their own transition process. They are frequently denied the opportunity to experience the

consequences of their decisions (Dee, 2006) and have transitions imposed upon them, rather than the transition being the result of choice and personal development (Byers, Hayhoe, Dee & Maurdsley, 2002). Transition planning for young people with PMLD can be a very complex and bureaucratic process involving many stakeholders, including parents/carers, health and social care professionals (Dee, 2006), and there is frequently conflict between the various stakeholders as to what is best for the young person, particularly between parents and professionals (Jacobs et al., 2018). Post-school transition planning for young people with PMLD coincides with the transfer of their care and support from children's services to adult services. This crossroads adds a layer of complexity because different funding sources apply and different teams of professionals take up responsibility for supporting the young people (Kaehne & Beyer, 2009). Transition planning for young people with PMLD is, thus, a very complex process and there are a wide variety of views about it, with a potential collision between the legal constructs of the transition process, varying models of disability and attitudes to inclusion or exclusion (Doyle, McGuckin & Shevlin, date).

Male (2015) reports that it is important in transition planning to focus upon the quality of life of young people with PMLD. Jacobs et al., in their review of transition to adult services, suggest that quality of life refers to meeting basic healthcare needs and providing activities and space for social interaction and stimulation. Yet quality of life covers the breadth of experience of a person. Schalock and Alonso (2002) identify personal, functional and social indicators of quality of life, including the following specific indicators for people with learning difficulties: material and emotional well-being, interpersonal relationships and self-determination. The relationship between the individual and the environmental context in which they live is a vital ingredient in quality of life and relates to both the immediate environment and the broader societal context that reflects the values and ethos of that society. To ensure quality of life for a young person with learning difficulties, the broader society must have a commitment to those who need significant support. This recognition links with principles of capability theory as discussed in Section 2.9 below. It is important at times of transition to remember that people choose activities that have meaning and purpose for them (Hughes, 2006). The day to day in which they can live their lives, acknowledging what they can do and what they would like to do. The views of young people need to be

expressed and respected by all those involved in the transition process. When young people with Autistic Spectrum Disorder are included in the meeting, they show a noticeable lack of engagement (Bell, Devecchi, McCuckin & Shevlin, 2017). Although young people with PMLD were notionally included in the previously mentioned study, in reality, their parents were included but they were not; there was no mention of them in the findings. This may indicate that, although young people with PMLD were included at the planning stage of the study, they were deemed unable to contribute to the actual study. Regarding the functioning and capability model proposed by Sen (2017), young people should be entitled to aspirations and quality of life as equal citizens. The capability approach concentrates on the types of life that people are actually living and how these can be improved; it is not merely a resource-led approach (Hart, 2012).

When preparing transition planning for young people with PMLD, it is important to remember that they will behave and communicate differently in different contexts, as demonstrated by Simmons and Watson (2014) in their empirical study of a young man in a variety of situations. Too often, decisions are made in the transition planning process based solely on what the young person has demonstrated in a restricted number of settings. This was a phenomenon I saw frequently throughout my career in special education. Young people with PMLD are outside the norm and can become dependent on stigmatising labels which may lead to resource allocation, but can also lead to stereotypical perceptions of and responses to young people with PMLD (Mercieca, 2013). Although young people with PMLD are dependent on the support and understanding of others, it is important to recognise their autonomy and to acknowledge that we live in an inter-dependent world. Young people with PMLD have a contribution to make to the communities in which they live (Mercieca, 2013).

The transition process for young people with PMLD and their families is a stressful time. It requires an adjustment for the young person but also for their families, who have to familiarise themselves with new personnel, environments and routines (Strnadova & Evans, 2013). Opportunities are limited for young people with PMLD when they leave school, and families are often forced to accept whatever opportunities are offered. Government legislation can change policies, making it difficult for families to understand what support is available and adding an additional layer of stress.

Professionals supporting the families often struggle to keep up with changing legislation and the subsequent implications.

It would be helpful if underlying principles to transition planning were established which remain independent of government legislation. Kohler, Gothberg, Fowler and Coyle (2016) suggest a five-pillar approach to transition planning which incorporates the key elements of student-focused planning, student development, interagency collaboration, family engagement and programme structure.

During the processes of planning and implementing transition, it is important that families' views are articulated but equally important that the young person has appropriate support and advocacy to enable them to express their independent choices and aspirations.

2.8 Advocacy

Advocacy for people with learning difficulties essentially assists them to speak up for themselves (Mencap, 2017). Advocacy takes various forms: in self-advocacy, people have the opportunity to speak for themselves to express their own ideas and aspirations; in citizen advocacy, a volunteer forms a long-term relationship with a person, getting to know them very well in order to be in a strong position to speak up for them; professional advocates can also be employed to speak on behalf of others (Chapman et al., 2012). When advocating for a young person with learning difficulties, there is always the potential that the advocate may be influenced by their own values and interpretations of situations. To avoid this, it is possible to develop a group advocacy, where several people form a group around the young person to understand and advocate for that young person. This enables a variety of perspectives related to the young person's aspirations to be noted and represented (Stewart, Mallett & Hall, 2015). This approach has been developed through the agenda of personalisation and individual budgets and has required personal development for staff and associates so that they actively seek to understand what is important to the young person. This can be achieved through developing person-centred teams (Sanderson & Lepkowsky, 2014).

Advocacy involving people with PMLD who cannot speak up themselves is very challenging (Walmsley & Johnson, 2003). It is difficult to establish a form of authentic communication that enables the young person to feel empowered to express their thoughts. This is recognised in current government strategic planning that also acknowledges the importance of support from people who know the young person well. The strategic plan identifies the application of Intensive Interaction, which encourages the young person to take the lead in communication, through any means that has meaning to the young person. This method develops the young person's sense of self-confidence and encourages them to communicate what is meaningful to them, as shown in the *Valuing People Now* Summary Report (D of H, 2009).

Elements of advocacy and person-centred approaches can be incorporated into the transition planning process. Person-centred approaches incorporate individualised planning to suit each individual person and their circumstances (Mansell & Beadle-Brown, 2012) usually as part of a circle of support for each person. The circle of support is constituted of people who know the person with PMLD very well and have that person's best interests at heart. Other elements included in this approach are self-determination, voice and the individual's views being appreciated and validated, as described in Section 2.7. Ware (2004) draws attention to the difference between making a choice and expressing a view. Young people with PMLD can, in supportive circumstances, make simple choices but expressing a view is more complex and challenging. This will be discussed in more detail in Chapter Three – Methodology. However, the respect that is enabled by this approach could be developed through an approach of social justice and capability.

2.9 Social Justice and Capability Approach

When you see a young person with very short legs, with very little control over his arm movements, in a wheelchair, with oxygen tubes fitted to his nose, what do you think? This question was posed by a young man who fits this description and who anticipates that others think about disability and the wheelchair. This young man entered the education system defined as having PMLD. He attended a mainstream primary school for one day a week and spent the rest of the week in a special school for pupils with similar needs. Yet, with the dedicated support of his mother, he has learned to read and

has started the campaign 'Teach Us Too' to highlight the need for high-quality education and expectations for all pupils, whatever their disability (Bryan, 2018).

The desire for social justice is only realised through action. Injustice arises from the unequal treatment of different members of society. These injustices are deeply embedded within the culture of the society (Hart, 2012).

As the example above illustrates, young people who are defined as having PMLD do not have equal treatment within society. Their disability and health issues are seen and attended to first, before considering the aspirations of the young person inside. Assumptions are made regarding educability and future development. For the theoretical physicist Stephen Hawkins, his academic prowess was recognised before the onset of his disability and he was able to benefit from all the necessary aids and medical treatment to enable him to lead a fulfilling life. This is an exceptional example, yet highlights the fact that his capability was recognised before his disability. A child born with multiple disabilities does not have the opportunity to show their potential; such children are defined by their disability.

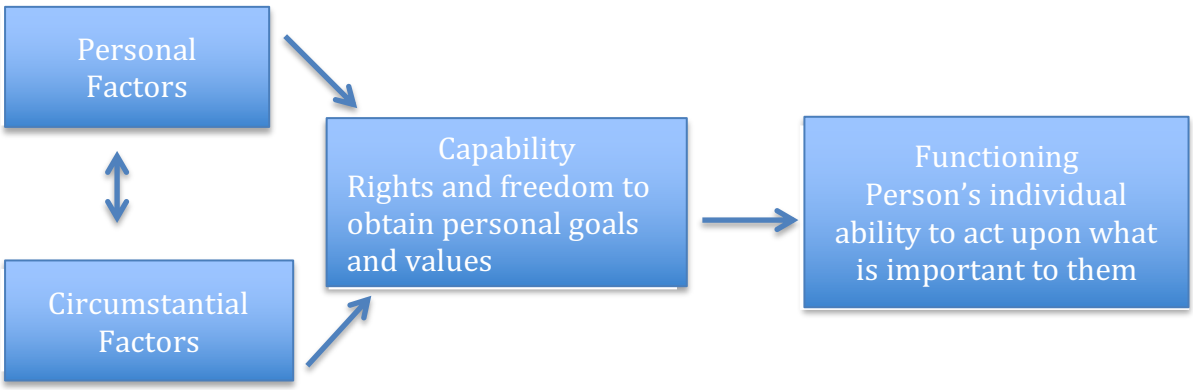
Perceptions of disability have a significant influence on the lives of disabled people, who may be viewed from a normative position. When disability is seen as a deviation from the normal, this can have a limiting effect upon disabled people's capabilities (Bryan, 2018). Disabled people are usually deemed to have a low capability of generating fulfilment and income for themselves and are, therefore, given a lower percentage of the total wealth of society (Sen, 2017). It is possible to view disability as a specific variable within a whole range of human differences, not based upon normative principles.

A person's capability is based upon their ability to take advantage of the available resources in order to lead a fulfilling life (Sen, 2017). Sen developed his ideas concerning capability and function based on a critical examination of the circumstances of the untouchables in the Indian caste system. His interest arose from a deep concern for social justice and personal agency. While a person may choose to fast although they have the freedom to eat well, people in an area of famine do not have that freedom and are compelled to fast. This has resonance with young people with PMLD, due to societal

perceptions and values regarding their disability; they are trapped without choice, like those trapped in the famine area.

A person's capability can be defined as the interaction between personal and circumstantial factors. For a young person with PMLD, personal factors include all aspects of their profound disabilities and the circumstantial factors are the environment and resources available to them. These are variable, and the young person has very little autonomy to influence these crucial factors; they have very limited personal agency. The limitation of capabilities has a subsequent effect upon a person's functioning, the roles and the participation that a person can achieve and value. The development of functioning is a direct consequence of the capabilities that a person can develop.

Figure 2.5 Capability and Functioning



Many young people with PMLD are unable to take advantage of the resources available to them because of the culture and circumstances in which they live. For example, Odyssey is a woman with PMLD who was unable to attend dental appointments or have blood tests without a general anaesthetic. With sensitive management of her personal budget, her mother has worked with a staff team to develop their understanding of Odyssey, her communication and anxieties. Odyssey is now able to attend dental appointments and has blood tests with confidence, amongst other things (Lyle, 2016). She now can take advantage of the resources available to her.

Currently, the culture surrounding young people with PMLD looks at their presenting problems and then identifies the resources that may meet these needs. Within this

current attitude to social justice, these young people are not valued as agents within the process of transition but are, in many respects, dependent on the attitudes of those in positions of power around them (Hart, 2012). There are some examples of this attitude beginning to change: in Scotland, an organisation is providing for hire a mobile changing facility for people with PMLD to enable them to access community activities such as concerts (PAMIS, 2021).

Social justice material relating to young people with PMLD is not specific, yet strands can be developed to offer an alternative perspective for them, in particular in the development of the application of capabilities and functioning, and this strand will be developed throughout the thesis.

Capabilities can be conferred upon people by the expectations of those around them. When there is an expectation of participation and capability, both the young person with PMLD and the people around them will make more effort. The treatment that people receive affects their functioning: if someone is expected to fail, the sense of failure is constructed around that person and they probably will fail or withdraw (Vorhaus, 2015). There is a need here for honesty, acknowledging individual differences (Imray, 2019).

Vorhaus (2017) argues that young people with PMLD should be entitled to share a common life within the community in which they live, where they participate, share and are acknowledged as young people with potential. The composition of the community needs to be fully understood. Many people with PMLD were removed from long-stay hospitals to become part of the community but are now in smaller facilities within the community and still not part of the wider community. Hence situations such as Winterbourne View and Whorton Hall develop (Colley, 2019). To be part of a common life, people are part of several communities, for example, family, social, work and interest groups.

2.10 Concluding Comments

Meaningful participation in the transition and research process for young people with PMLD remains a challenge, despite changes to legislation (Nind & Strnadova, 2020).

This will be discussed in more detail in the methodology section. It has been shown that an in-depth case study is a meaningful way to understand and develop the understanding of people with PMLD, as identified by Kellett (2004, 2005) and Jacobs et al. (2018). This will also be developed further in the methodology section.

In my professional role, I was aware of a discrepancy between political policy and practice and this is endorsed in the literature (Jacobs et al., 2018). It may be interpreted as a reflection of the confusion that exists within society around the value placed upon people with PMLD. There is a lack of choice for young people with PMLD (Jacobs et al., 2018). This is also endorsed by the understanding of the quality of life for young people with PMLD as discussed in Sections 2.7.6 and 2.9. The recognition of these discrepancies will influence the research design, as discussed further in the methodology section.

Throughout the literature review, there is an acknowledgement that young people with PMLD have very particular issues in relation to communication and transition. There is a need to draw together the existing knowledge of young people with PMLD, their communication and post-school transition planning and to develop this existing knowledge so that these young people may be able to participate more fully in their own post-school transition planning, using communication techniques that are comfortable and empowering for them.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

Identification of Project

My research focus arose from a deep sense of disquiet when I was the headteacher of a special school (see Introduction 1.2). Profoundly disabled young people consistently had no authentic voice in their post-school planning process. As a class teacher and in various other roles, I had been aware of the lack of involvement of young people with PMLD. When I became a headteacher, I thought this position of authority would enable me to effect change in this situation but, in reality, I found that the diverse roles and responsibilities of a headteacher distracted me from the detailed research necessary in order to effect realistic change. Through the literature. I developed my understanding of young people with PMLD, their communication and the transition process (see Literature Review 2.4, 2.5, 2.7) and saw that methods needed to be identified to enable young people with PMLD to be more involved. It was from this identified need and the literature that the research question unfolded. From my perspective, to deny the young people access to influence something very important to their future was a matter of social justice. It is my intention in this project to make a difference to the lives of people with PMLD.

Research Question

How can young people with PMLD influence their own post-school transition planning process?

Although the research question seems straightforward, the issues that it raises are complex and there are many strands to consider. Several subsidiary issues also need consideration. A core principle of the current transition planning procedure is the participation of the young person. In my practitioner experience, however, I perpetually noted the exclusion of young people with PMLD from their own transition planning process. In order to challenge this, the current research must include the participation

and voices of the young people. This will generate meaningful data that has the potential to transform the lives of these young people (Nind, 2014). Participation for young people with PMLD can mean the creation of spaces where experiences can be shared to foster a deeper shared understanding (Nind, 2014). In order to influence their post-school transition planning, young people need to be able to express themselves. They need to be listened to and to be understood and, when they express themselves, their communication, in whatever form, needs to be valued. The value of a young person's communication reflects the value that is placed upon that individual young person (see Introduction 1.7).

All young people who have an Education Health and Care Plan (EHCP) are required to begin the transition planning process in Year 9. The organisation of transition planning meetings is usually the responsibility of the school that the young person attends. The school is responsible for identifying and inviting relevant people to an annual meeting to develop plans for the young person. The transition planning process, although set out in the SEN Code of Practice, varies according to the interpretation of individual schools.

The structure and the organisation of the transition planning process has an important influence on the young person's ability to influence decisions about their future. This is another important consideration when approaching the development of the research question.

Stance of Project

The project takes a positive, enabling approach to young people with PMLD. It is inclusive and endeavours to facilitate the participation of young people. The individual communication style and abilities of the young people are validated throughout the project. Innovative methods of communication with young people with PMLD are used (see Literature Review 2.6), methods that are unusual in the field of research. These are combined with the open reflective principles of grounded theory and case study. This approach maximises the participation of the young people, despite the complex problems they have to manage in their daily lives. The combination of these methods enabled an open-ended analysis of the data, scrutinised without bias. Central to the

project is the desire to investigate methods through which the young person's reality may be expressed, validated, and respected.

The case studies in the project generate deep knowledge of the three individuals through a thorough reflexive approach. There is potential for some triangulation across the case studies. The depth of each individual case demonstrates the need to treat each young person with PMLD as a unique individual, each with an individual combination of profound, complex difficulties. This is important to consider in the transition process for young people with PMLD.

The project is constructed with particular underlying core principles, as discussed below.

Core Principles

Social Justice

Social justice is a sense of fairness (Sen, 2017) which can be affected by perceived social norms as determined by dominant groups within the society, with any behaviour outside the perceived norms seen as a deviation (Becker, 1963). Deviation from the norm can be understood as the consequence of the response of other people to a given person's actions (Becker, 1963). The unusual behaviour of young people with PMLD, which is outside that perceived to be of normal young people of their age, can influence others' reactions to them (see Introduction 1.8).

Social Justice and PMLD

Young people with PMLD are often defined by the reaction of others to them. Their idiosyncratic behaviours are difficult for people to understand. The behaviour of a particular group may be unacceptable to the dominant group (Edgerton, 1979), based upon attributes such as race, gender, class and disability. These are superficial attributes which carry no moral value (Roaf & Bines, 1989) but young people with PMLD experience these attitudes frequently. Social injustice can be the consequence of cultural and economic exclusion and disadvantage (Riddell & Weedon, 2017). Young people with PMLD are entitled to participate in making their own decisions and to have

a good life as part of their community (Francis & Mills, 2012). This project attempts to address this aspiration for social justice.

Emancipatory Research

Emancipatory research is conducted from a perspective where the production of knowledge benefits the disadvantaged group (Edwards & Holland, 2013), and the skills and knowledge of the researcher are used to empower disabled people (Barton, 2005). The power dynamic within emancipatory research remains a problem: the powerful are rarely researched because they have the power to protect themselves from scrutiny, and researchers rarely reveal as much about themselves as those they are researching (Oliver, 1992). Emancipatory research should pass the control to the participants, in this case, the disabled young people (Johnson, Walmsley & Wolfe, 2010); however, the severity and complexity of the disabilities of the participants in this project present challenges as to the degree to which they can be in control (see Introduction 1.6).

Emancipatory Research and PMLD

In practice, emancipatory research when working with young people with PMLD primarily concerns the self-realisation of both the young people and the researcher (Oliver, 1992). Until the roles within the research process can be developed to enable an equal partnership between the researched and the researcher, it is probably most realistic to conclude that the researcher acts as an advocate for the young people engaged in the research (Johnson et al., 2010). Research with young people with PMLD can essentially be for them and endeavour to be with them in as many ways as possible. The application of these principles can develop the research process and increase appreciation and understanding of young people with PMLD (Nind & Strnadova, 2020).

Interpretative Approach

An interpretative approach evolved in research which was subsequently considered to be as alienating as the positivist approach. Emancipatory research has gradually evolved from a positivist paradigm, which assumed that social worlds could be studied in the same way as the natural world while acknowledging the socially constructed influences on the research, such as the researcher's previous experience (Oliver, 1992).

This heralded the end of what could be termed research tourism (Oliver, 1992) when the researcher was an onlooker, not truly engaging with research participants.

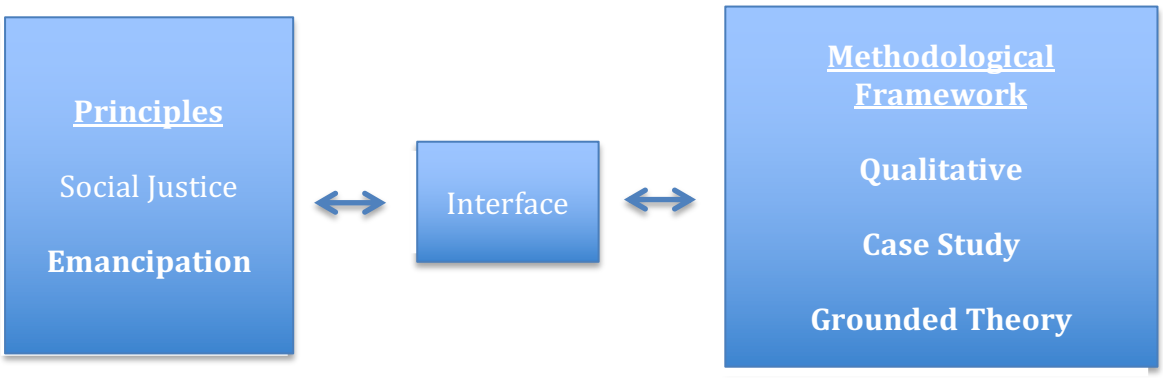
Framework

The core principles are set within a qualitative research framework. The research has an interpretive approach (Mason, 2002) to the in-depth meaning of the communication strategies used by young people with PMLD as they prepare to leave school. It was necessary to investigate over a prolonged period and from a variety of perspectives (Miles et al., 2014) the meaning of the young people's communication and life situations. A flexible approach was required, able to respond to and note the idiosyncratic nature of young people's communication (Mason, 2002). These are essential features of a qualitative enquiry.

The project develops work initiated in a preparatory pilot study which is described in more detail in Section 3.2. The substantive project comprises three in-depth case studies of young people in real-life contexts (Yin, 2014). A further literature search relating to the methodology identified that the multiple case study structure provides a good framework for the research project. Data will be generated from interactions between the researcher and each young person and conversations with significant people in each young person's life, providing sources of evidence and including the realities of several contributors (Yin, 2014).

Grounded Theory principles are based on the perspective, context and experience of the people involved and are applied to the analysis of data through categorising and coding material from the various sources of evidence (Glaser & Strauss, 1967). The data is considered to emerge from the subjects and situations in which the research is set (Kelle, 2007). This analytical process provides deep on-going insights. The on-going reflections of the researcher enrich the Grounded Theory research process; within this research project, Grounded Theory principles are applied from a practitioner base (Glaser & Strauss, 1967). The key principles of the research project and the inter-relationship with the methodological framework can be seen in Figure 3.1.

Figure 3.1. The Principles and Methods of the Research Project



Ethics

Ethical considerations are particularly important when researching with vulnerable young people. Throughout the project respect, sensitivity towards the young people was vital. At the beginning of the research process, when gaining consent and permissions from significant people such as parents, it was important to establish a respectful manner in which consent could be obtained from the young people themselves, consent that was meaningful for the young person and valid within the context of the research project. As the research developed, other ethical issues emerged that had to be resolved within the context of the research (Wiles, 2013). These are discussed in more detail later in this chapter.

Development of Methodology

Several critical incidents (Kamler & Thomson, 2014) were key in the methodological development, representing challenging realisation points. During the pilot study, I realised that the methods I was using were not fit for purpose. When I reflected upon the use of observations and interviews in the pilot study, I realised that they did not afford the young people the true participation to which they were entitled. There was an imbalance of power between myself as the researcher and those people who were notionally the subject of the research.

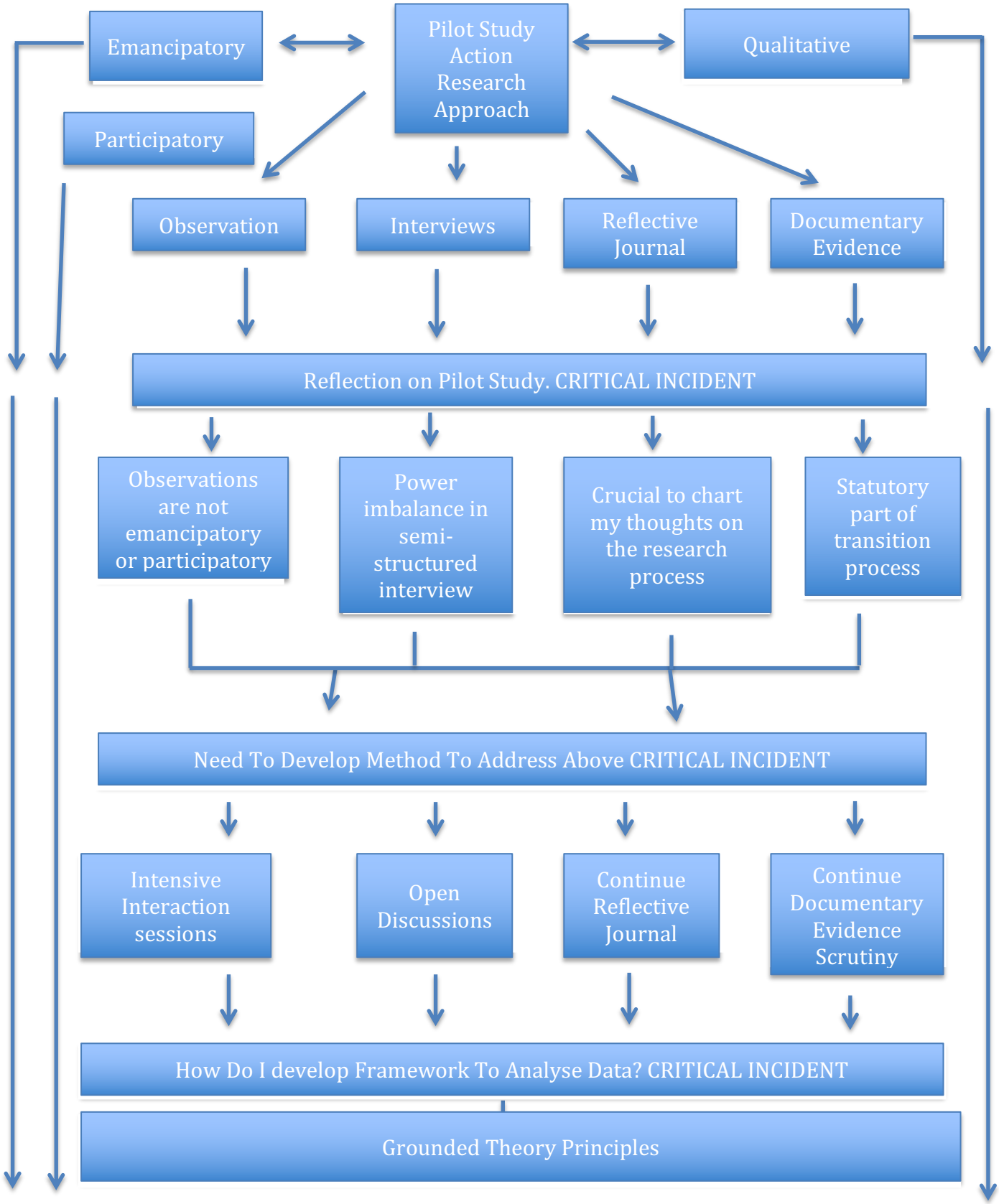
Following reflections on the pilot study, I identified the possibility of using Intensive Interaction methods to provide opportunities for young people to express themselves

directly with me without the mediation of other people. I realised that I was in control in interviews with staff and the young person's mother, although I had thought these were open-ended interviews. To have discussions about the young person would allow a dialogue on more equal terms. Building on a recognition of the value of reflection identified during the pilot study, a definite reflective pattern became part of the project methodology. Data collection activity was followed by reflection which often generated critical incidents in the development of the methodology. This approach developed the exploratory nature of the project.

Grounded Theory provides a framework for the development of the process of reflection and reflexivity. For example, Katy's reaction when I offered her an iPad in an interactive session (see Findings 4.4.1) was to repeatedly throw it on the floor: she obviously did not want to include the iPad in the session and this led to the adoption of a different approach in subsequent sessions.

Figure 3.2 provides an outline of the sequential development of the methodology.

Figure 3.2 Development of Methodology: A Journey of Discovery



3.2 Pilot Study

Outline

The pilot study was a single case study conducted before the substantive research project. It grew out of my professional concerns about the lack of involvement of young people with PMLD in planning for their futures. Prior to the pilot study, I conducted a general search of the literature in this field, including material relating to social justice, emancipatory research, case study, observation and interview. This search informed the planning of the methodology of my pilot study.

The pilot study was conducted with a Year 11 student with PMLD in her final term in a special school. The pilot project had three strands: to review the documentary evidence relating to the post-school transition planning process for the student; to observe the student in various settings throughout the school day to note how she initiated communication; to conduct semi-structured interviews with significant people in the student's life.

Throughout the pilot study, I adopted the role of a non-participant observer, as I considered I would be able to record the young person initiating communication more effectively in this way (Yin, 2014). The observations took place within the normal school day including lessons, break and lunchtimes (Walker, 1987). One observation took place off-site when the young person went sailing, and the impact of the different locations was significant (Yin, 2014). Throughout, I kept observation notes. I chose not to use video recording because I considered this would be more intrusive and distracting both to the young person and the rest of the class. It may also have inhibited staff. The young people were unaware of the purpose of the observations but the staff were aware.

I asked other people about the young person in a series of interviews but did not engage directly with them. I approached the interviews expecting the interviewees to respond to the agenda that I had set for a respondent-style interview (Powney & Watts, 1987) as I had specific questions I wanted to ask. Throughout the pilot study, I kept a research

journal that recorded some of my reactions to situations within the pilot and, at times, became a dialogue with myself. The transition documentation for the young person who was the subject of the pilot study was scrutinised.

I learnt a great deal from the pilot study; it had a significant impact on the methodological design of the project, as discussed in the following section, and on the development of the research question.

The Pilot Study: What was Learnt?

General Points

The pilot study led me to question the authenticity and efficacy of my approach to emancipatory, inclusive research and revealed that I needed to adopt innovative approaches to the research methodology.

In the course of the pilot, my understanding of case study work developed. The pilot had been explorative; the substantive project would develop the exploration but would also be investigative. The project would draw upon multiple sources of evidence and would be set in a contemporary world context.

The Analysis

The analysis of the pilot outcomes revealed assumptions based on the practitioner experience I had brought to the research. Through my practitioner lens, I was aware of the marginalisation and disempowerment of young people with PMLD. As a researcher conducting the pilot study, the disempowerment and power imbalances became evident on many levels that, as a busy practitioner, I had not taken sufficient time to reflect upon.

In schools, it was accepted practice to try to find out more about a young person with PLMD by observing them in a variety of settings. For example, when the educational psychologist wanted to know more about a young person with PMLD, they would come into school, read previous reports, speak to parents and significant staff and observe the young person. In the pilot study, I applied similar practices to those accepted within school settings but realised afterwards that this approach was naïve and fundamentally

not emancipatory. To find out more about any other young person, I would have spoken to them directly. It is a significant challenge to establish methodologies that give young people with PMLD a voice in research and their lives (Simmons & Watson, 2014). I referred back to my practitioner knowledge. Thorough research with these young people required an approach that enabled the young people to participate as equals with the researcher.

Interviews

Without exception, it was very difficult to maintain my agenda during interviews. The interviewees simply wanted to tell me about the student, their involvement with the student and his/her particular aptitudes. I realised that the interviewee had very little opportunity to talk about the young person and their relationship with them and had therefore used the opportunity to explore their thoughts and perceptions (Powney & Watts, 1987) in a more informant style of interview. A revision of my interview methodology for my research project was required.

Reflective Journal

I kept a reflective research journal during my pilot study and found it very useful and enlightening. It helped me to gather and order my responses to the experiences within the pilot and was then developed and included as a data source within my main project. This can be developed by applying heuristic, self-reflective approaches. The researcher needs to develop self-dialogue when applying this approach, to record their own intuitions, perceptions and reactions. Out of this increased sense of inner awareness, a deeper sense of meaning of the situation evolves (Moustakas 1990). This approach is particularly appropriate when researching young people with PMLD because the perceptions of other people have a very powerful impact upon the lives of young people with PMLD. The more that the researcher probes their own perceptions and reactions the more informed they will be. This will enable them to understand and effect change in the perception of young people with PMLD. Rigorous self-analysis will provide evidence for change in a deep-seated cultural status quo.

Transition Documentation

The transition documentation revealed that those involved in the transition planning process were involved in a mutual deception (Glaser & Strauss, 1967) regarding the severity of the young person's difficulties. They perceived the difficulty experienced by the young person in diverse ways and tended not to explicitly address the severity of the young person's difficulties. This experience was similar to the work with dying patients conducted during the development of Grounded Theory when everyone around the dying person knew the person was dying but nobody explicitly spoke about it or acknowledged it.

Development Following Pilot

Following the pilot study, specific areas were identified for further work, including case study, Intensive Interaction, participatory research, Grounded Theory and heuristic research methods.

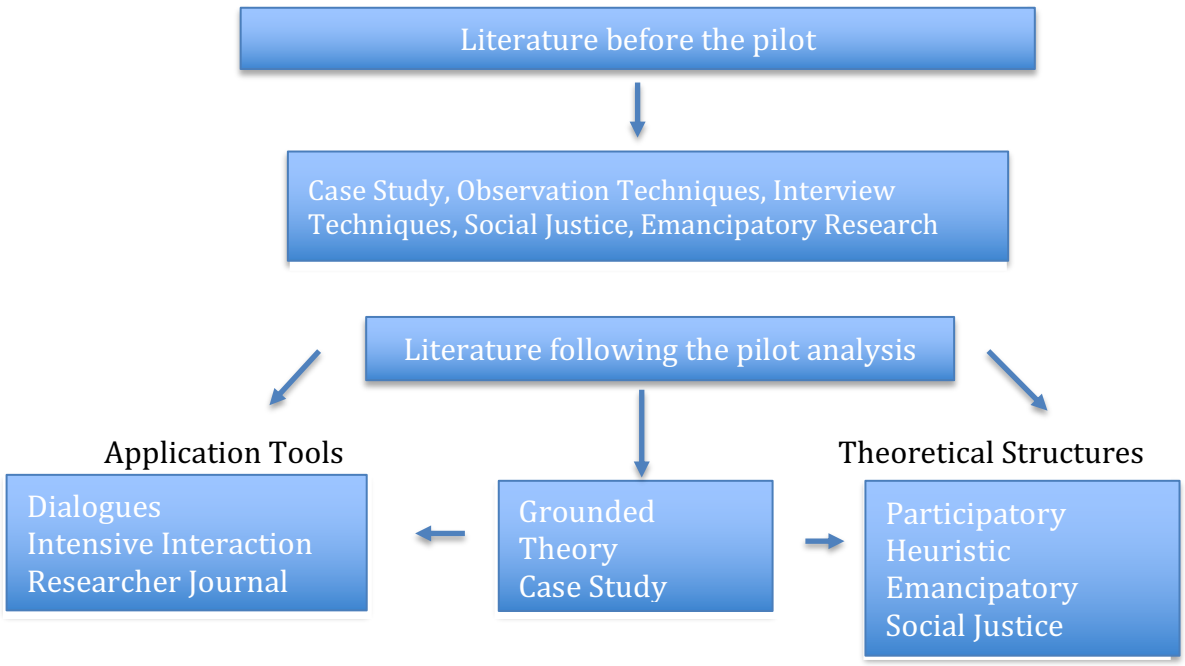
Alternative methods of enabling young people to be more effectively involved in the research process were identified (see Figure 3.2, critical incident). I had seen methods used very effectively in education settings that were untried in the field of research (Etherington, 2004). I identified Intensive Interaction as a tool that could be used to enable young people with PMLD to express themselves and make a valid contribution (see Figure 3.2). Intensive Interaction is a way of two people spending time together, developing shared ways of communication. The pair comprises a skilled communicator and a young person with PMLD (Hewett et al., 2012) who, in this way, become equal communication partners (see Literature Review 2.6). Using Intensive Interaction in this way is innovative and has the potential to reveal the young person's values, likes and dislikes without others needing to speak for them, inevitably applying their own interpretation to the lives of young people with PMLD.

There is an identified need for methodological innovation when researching young people with PMLD (Simmons & Watson, 2014). I, therefore, carried out a more in-depth methodology literature search. Figure 3.3 illustrates the development of the literature search following the Pilot Study. This revealed many aspects of multiple case study framework appropriate for the research project.

The future research required a conversational approach between the researcher and the people who are significant to the individual young people to develop shared knowledge (Brinkmann & Kvale, 2008). There is an inevitable power dynamic in an interview situation, but a conversation-style approach enabled a shift of power and control from one to the other throughout the interview session (Edwards & Holland, 2013) and encouraged the development of shared meaning and speaking honestly, rather than each party trying to say what they think the other wants to hear (Hammersley, 2008).

The pilot had been an exploratory investigation with methods influenced by my practitioner experience. After the pilot study, the research question became more focused and challenging. The research became the desire to answer a question beginning 'How?' This type of question shows an underlying assumption that there is a way which needs to be found. The research question became challenging due to the complex nature of the young people's difficulties and the culture which has developed around them. The outcomes of the pilot, subsequent researcher reflections and literature searches contributed to the research design. From a general stance in the pilot study, a clear structure evolved, as shown in Figure 3.3.

Figure 3.3 Development of Research Design Following Pilot



3.3 Research Design
Introduction

It is important to be clear that the intended methods are fit for the purpose of the research (BERA, 2020) as defined by the research question. The research question focuses on giving young people with PMLD greater influence over planning their lives when they leave school. The research design intended to develop a methodology that was inclusive and encouraged the participation of those who will potentially benefit from the research. Positivist, quantitative research approaches would not capture the voices of the research participants (Simmons & Watson, 2014). The comparative data gathered in traditional quantitative methods would not enable a deep appreciation of each young person or contribute to a deeper understanding of each individual with their unique combination of disabilities. These must be accommodated within the search for deep meaning for young people with PMLD.

Qualitative, interpretive approaches develop an in-depth understanding of the multiple realities of young people's lives. Young people with PMLD are a small minority group (see Literature Review 2.4). It was important to understand the subtle nuances of behaviours that young people with PMLD demonstrate as part of their communication (Simmons & Watson, 2014) (see Literature Review 2.5).

As part of the research design, methods to enable deep understanding were applied to individual young people with PMLD. The transition documentation is designed to record the transition process for a large diverse group of young people with SEN. I realised, however, that it was not fit for purpose for young people with PMLD and their complexity of need. The research design, therefore, needed to include scrutiny of the transition processes and documentation in order to develop recommendations that reflect the aspirations and complex difficulties of young people with PMLD.

Design Principles

The core principles and framework of the substantive research project are outlined in the introduction to this chapter (Section 3.1).

The research design was based upon democratic and meaningful relationships with those people who were the subject of the research (Nind, 2014). It was essential to be realistic about how young people with PMLD could authentically participate in the research process. While it is easy to blame the lack of research in this field on the complex difficulties of young people, it is important to acknowledge that the problem lies rather with the inadequate research tools available to work with these young people (Nind, 2014). The literature encouraged me to be imaginative in creating methods that would be effective with these hard-to-reach young people. I read that a researcher had been able to help women in Sudan tell their stories by using beads (Nind, 2014) and sought to apply this type of bespoke innovative approach to the research project.

The development of participatory research can be seen as part of a political emancipatory movement to provide marginalised groups with a voice. The research can become a means by which they can express their voice; everyone has a voice but needs to have a means of expressing that voice (Bradbury-Jones, Isham & Taylor, 2018). The research question embraces the need to identify methods that give young people with PMLD a means to express their voice. Through the literature and my previous experience, Intensive Interaction was identified as a potential means of giving young people a voice in the research process and their transition plans (see Literature Review 2.6). Intensive interaction is not usually used as a research tool, and the use of this method of facilitating communication in an equal relationship makes the research design of this project innovative. It is difficult to obtain the views of young people with PMLD with any certainty but this uncertainty should not prohibit the endeavour to include them.

For this research design, participatory research includes the active involvement of the participants to value and develop an understanding of their unique experiences (Bradbury-Jones et al., 2018). Their involvement is realised predominantly through interactive sessions and the power and control these give them.

The participatory research methods created a closed space between me (the researcher) and the participant, creating opportunities for new power dynamics and relationship opportunities (Mercieca, 2013).

Case Study

It was important to sample before beginning the case study (Miles et al., 2014) and this was achieved in a pilot study. To achieve the depth demanded by the research question, I decided to focus on a small number of cases for the main study. To attempt to work with more cases would have compromised the depth essential to address the research question.

The format and principles of a case study matched the essential elements of the project which asks a 'how' question. This is an investigative project, seeking to understand and give enhanced meaning to real-life situations (Kyburz-Graber, 2004). The boundaries between the young people and the contexts in which they exist are not always clearly defined (Yin, 2014), which fits with the principles of the case study. The case study techniques used include observation, scrutiny of documentary evidence, discussions and reflections. These can be considered as methods in their own right but, for the purposes of this project, needed to be used together under the umbrella of the case study model.

The project was a multiple case study that comprised three individual cases, each case being a unit of analysis. Each case draws upon similar methods and locations for data collection, providing an opportunity for the in-depth study and analysis of three individual cases (Miles et al., 2014). The replication of and deviation from themes are expected (Yin, 2018) and the combination of these factors provides a platform for the analysis of the data. Each young person with PMLD is unique, with idiosyncratic qualities that the research project needed to capture. The pilot study highlighted that the substantive project needed to explore in great depth issues related to young people with PMLD and post-school transition. The research methods needed to seek depth and reflect each young person's individuality and complex combination of disabilities. Within the case study framework, ethical issues were identified as important (Yin,

2018). This was particularly relevant in this project as all the cases involve vulnerable young people. This issue will be discussed in greater detail later in this section.

It can be of benefit in case study methodology to apply a mixed-method approach incorporating other complementary methods (Yin, 2018). In this project, Grounded Theory principles were used alongside the case study framework.

Grounded Theory

Grounded Theory evolved from the close observation of those involved with dying patients who are trying to maintain composure in a distressing situation and dignity in front of the dying person (Glaser & Strauss, 1967). There are parallels when dealing with profoundly disabled young people as those involved are trying to rationalise the extent and impact of the disability.

The principles of Grounded Theory provide a flexible responsive structure to the project. The application of these principles can create a space when unexpected outcomes can occur and allow an imaginative relationship with the data (Bryant & Charmaz, 2007). Grounded Theory offers a means to construct theories from the realities perceived by the participants (Silverman, 2014). It also acknowledges the importance of the context of the participants' experiences (Birks & Mills, 2015). Close attention is given to the emerging data (Glaser & Strauss, 1967) in a non-judgemental manner. This should be conducted in a realistic context with the people who are participating in the project through a process of grouping the data into categories using memos, the equivalent of snapshots of incidents within the data (Birks & Mills, 2015). Deep knowledge is generated by repeating the process of data collection, writing of memos and development of categories. The coding process and the formation of categories provide structure for the analysis of the data (Bryant & Charmaz, 2007). The understanding of the data is revised and reviewed in order to establish a theory of some form of truth about the situation.

The principles of Grounded Theory fit well with the aspirations of this project, although modifications are necessary as noted in the Analysis section of this chapter. The data collection period was relatively short. The principles of categorisation were applied but

the process was less detailed than would be the case in a more extended application of Grounded Theory. From the available data, it was possible to generate greater insight for participants in the transition process and, thus, give the young person with PMLD greater opportunity to have their views included in the process. The research process fits with the thorough, deliberate manner required to really get to know and understand young people with PMLD.

This project was limited in scope and cannot look at multiple samples over extended periods (Bryant & Charmaz, 2007). It was anticipated that this project would examine emerging phenomena (Urquhart 2013) and possibly highlight the need for further research, but not that a theory would be developed as a direct outcome. Although the project includes many aspects of the Grounded Theory methods (Bryant & Charmaz, 2007), it does not apply Grounded Theory in its truest form.

Inter-Relation Case Study and Grounded Theory

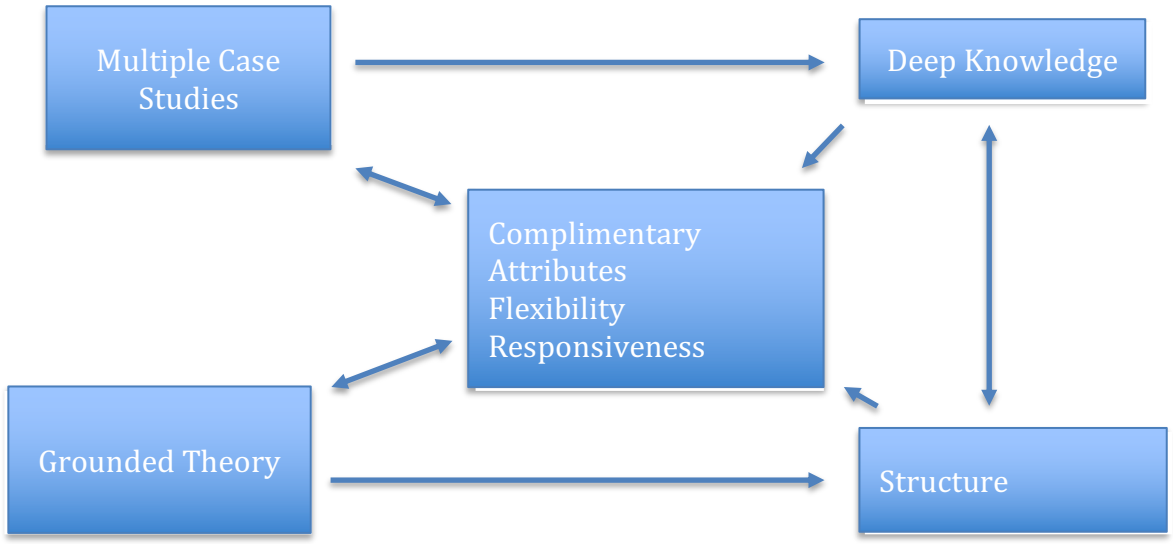
In order to capture deep knowledge and the voice of the young person, it was crucial to identify a methodology that provided a structure for the data analysis alongside flexibility and responsiveness to the emerging data (Bryant & Charmaz, 2012). I intended to develop a method that allowed the researcher to inhabit a common space with the participants (Birks & Mills, 2015).

The case study provided a structure and boundaries to the research around each young person. Each young person with PMLD has a unique combination of difficulties but the multiple case study structure allowed for common strands to emerge across case studies. As the commonality emerged, it was not imposed through the research design. The approach provides an in-depth focus on each young person, the people associated with them and the documentary evidence for each transition process. It provides clarity to what was and what was not included (Miles et al., 2014).

The identification of Intensive Interaction as a research tool emerged from the analysis of the pilot study data. It was an appropriate tool as it facilitates empowered communication for the main participants, all of whom have communication difficulties.

Grounded Theory enables the identification of emerging patterns for each individual and provides a method to drill down deeply into the data so that deep meaning may emerge. This was important when trying to understand the deeper meaning of the communication of young people with PMLD and the context in which they lived. Many layers of complexity affect the lives of young people with PMLD and, by drilling deeply, a greater understanding of the young person emerged. The outcomes of the process will benefit individuals but commonalities across case studies also may emerge (Miles et al., 2014). The principles of grounded theory, in tandem with the case study and deep reflection, enabled a reflexive response to the data (see Figure 3.4).

Figure 3.4 Inter-Relationship Between Case Study and Grounded Theory



Sample

The project includes three case studies and was designed with a multiple case study structure. The extent of the young people's disabilities means that they and their families have very unpredictable lives and it was, therefore, necessary to be flexible and responsive to circumstances. Responding to the different circumstances as they arose provided realism to the research as it indicated a range of the real issues that young people and their families experience at the point of transition from school. The cases selected for the project were at different stages of the transition process: one was in Year 9, just beginning the process, one in Year 10 and one in Year 11, reaching the end of the transition process. Each young person attended a special school; two attended the

same school. Working in two schools added variety to the project although this was not a specific criterion for selection. The label PMLD covers a range of disabilities, as noted in the Literature Review (2.4) and Introduction (1.9), and interpretations of the range of disabilities and how they contribute to the definition of PMLD differ. Ware (2001) states that a young person with PMLD will have more than one of the following disabilities: significant motor impairment, significant sensory impairment, complex health care needs, or dependence upon technology. Jacobs and McMahon (2018) define a young person with PMLD as having rudimentary communication, requiring substantial supervision and being reliant upon others to make life-changing decisions. For the purposes of this study, PMLD was seen as a spectrum and a combination of disabilities. Each young person selected to participate in the project has a combination of various disabilities. All have a profound cognitive disability; have had their disability from birth and their disability will remain with them for the rest of their lives. The three case studies illustrate a range of the different disabilities and combinations across the spectrum of PMLD as defined in the specialist contexts in which I carried out my research. Thus, the project was representative of a broad range of young people who may be labelled as having PMLD.

Harry is a young man who was in Year 10 at the beginning of the study. He has no verbal communication but uses limited facial expression, vocalisation and gesture although he frequently chooses not to use even these very limited forms of communication. Harry often chooses to be in his own world in his wheelchair with his head hung down. Communicating with Harry can be very challenging and people may give up or simply guess what he wants or needs. Harry has significant health issues: he experiences epileptic seizures and is a wheelchair user. He has suffered a couple of strokes that further restricted his independent movement and following which he required a tracheostomy to help him to breathe, although this has subsequently been removed.

Katy was in Year 9 at the time of data collection. Katy has cerebral palsy and is hemiplegic; she has the full use of one arm and hand, but the other has very limited movement. Katy is a wheelchair-user; she is unable to weight bear and needs support to maintain a sitting position. She has no verbal communication but uses a variety of communication strategies including facial expression and vocalisation that she has

developed herself. Her communication is vicarious as she is dependent on others accurate interpreting it. Katy also has epileptic seizures and is dependent upon others to attend to her care requirements and to feed her.

Linda is a young lady with Downs Syndrome. She has no verbal communication although she can use a few signs and is learning to use an iPad as a communication aid. However, Linda's use of signs and the communication aid is not functional: she requires insistent prompting to use either form of communication and then only in a very echolalic mode. Linda was diagnosed as being on the autistic spectrum before she started school. She is dependent upon others to supervise all her personal needs and will not feed herself unless constantly prompted to do so.

From the descriptions above, it can be seen that the young people identified for this project represent a broad spectrum of PMLD within the definitions given earlier in this section and the Literature Review (Section 2.4).

3.4 Methods

Introduction

Data were generated in locations familiar to the participants: at school for the young people and school staff; in the family home for parents. The sessions were planned at times that would be convenient for the participants. The data generation was designed to be empathetic to the participants, understanding the pressures and organisational issues that can emerge in a special school environment.

Intensive Interaction and Associated Reflections

Following the pilot study and subsequent reflections (Methodology 3.2) Intensive Interaction (Literature Review 2.6) was identified as a method that could be used to have direct, meaningful communication exchanges with the young people involved in the project. Each young person engaged in individual, weekly, interactive sessions of approximately 20 minutes with the researcher over two terms. The interactive sessions took place in a location that was comfortable and familiar for the young person; for two young people this was in a small quiet library area and, for the third, it was a designated quiet area of the classroom. At the end of each session, the researcher reviewed the

notes along with their reflections. This often led to slight modifications in the following session.

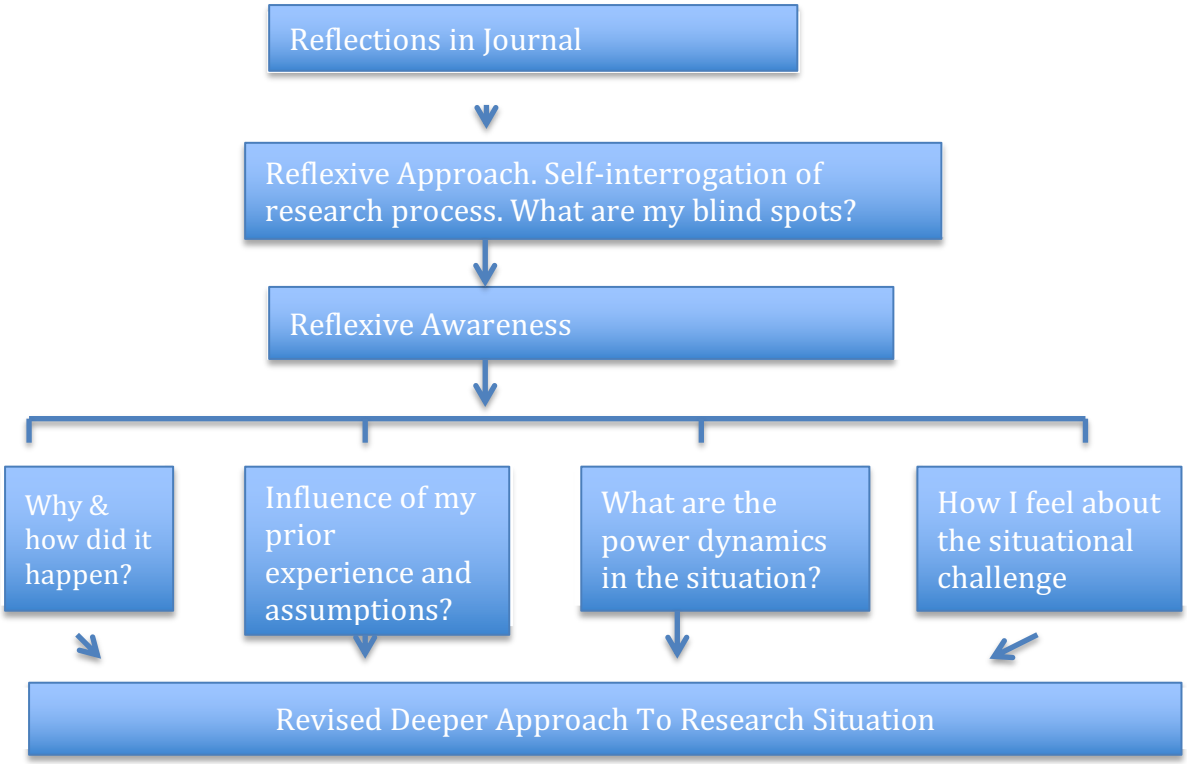
Observation

A teaching assistant familiar to the young person, acting as a research assistant, observed and made notes under designated headings as each session unfolded. I regarded it as important that the young person felt that the researcher was alongside them and did not anticipate they were in any way to be directed (Simmons & Watson, 2014) as young people with PMLD are not used to being given autonomy.

Research Journal

The research journal proved a vital part of the pilot study (Methodology 3.2). Building on the identified value of this experience, a research journal was kept throughout the main research process. A crucial part of the methodology was the development of honest reflections as the research process unfolded (Etherington, 2004). The researcher was able to acknowledge her experiences and reactions to the research process and these represent a specific element of the research data, as they form an integral part of the research journey. A reflexive approach to the research journal can significantly impact the quality and vitality of the data generation and can unite the subject and object of the research (Kamler & Thomson, 2014). Many of the reflections slightly alter aspects of the research process, forming critical incidents (Kamler & Thomson 2014) and several of these arose as outcomes of reflection on previous stages of the research journey. In this respect, the development of the methodology can be viewed as a journey of discovery.

Figure 3.5 Reflective Journal Leading to a Reflexive Approach



Interviews/Discussion

Following the reflections on the pilot study, the main project used informal discussions with the sole purpose of discussing the young person, a mutual exchange between two people (Brinkman & Kvale, 2008). In some respect, the discussions could be viewed as a social occasion (Hammersley, 2008), an opportunity to share experiences of the young person. Discussions took place at the beginning and the end of the research period between me, as the researcher, and the parents of two of the young people. There were also discussions with individual school staff who worked closely with each of the young people at the end of the research period. I made notes immediately following each discussion. The discussions were designed to enable a current life-story approach, where those involved could see the young person as a unique individual with specific characteristics, qualities and attributes (Simmons & Watson, 2014). They provided insights into the context in which the young person was living and the different relationships within the young person's life.

Documents

The documentary evidence for each young person comprised the statutory documents required for each young person during the period of preparing for their transition to leave school. These comprised annual review reports, the annual review of their statement, the transition plan and the change-over document from statement to EHCP. During the period of the project, the documentation for SEN pupils changed from each pupil having a statement to having an EHCP, hence the need for transfer documentation. Transition planning starts in Year 9; in each subsequent year, the transition plan is subject to an annual review. Thus, the participant in Year 9 has an initial transition plan whereas the participants in Years 10 and 11 have transition review documentation.

3.5 Ethics

General Issues

Ethical considerations involve the beliefs and values of groups within society, including the macro beliefs of society and the micro values of individual families and people within these groups. Pascal and Bertram (2009) identify the importance of acknowledging the views of these groups within the research project and of awareness of the context within which the views exist. Some families may see their child with PMLD as remaining a child forever; society as a whole may consider that young people with PMLD are not capable of expressing themselves. There are many ethical issues to consider when planning an educational research project, as the researcher has a responsibility to all participants (BERA, 2011). Iphofen (2009) draws attention to the fact that research can lead to the development of human rights. All participants must be treated with respect, dignity, and sensitivity and the safety and well-being of the young people must be paramount. Any cause for concern in this respect must be disclosed to the appropriate authority. All data must be kept secure and protected from potential abusive use, particularly pictorial and video images (Hawe & Hadfield, 2011). Information about the research should be shared with the participants in a manner and form that they can understand and careful consideration must be given to gaining consent to participate.

Issues Related to Research with Young People with PMLD

When researching marginalised groups, it is important to make clear that expectations of change are not assumed as a consequence of participation (Whyte, 2005). Significant ethical issues are associated with research involving vulnerable young people with PMLD. Consent to participate should be given by the person in the role of guardian (BERA, 2011). There may be a perception that young people with PMLD may not be able to give consent due to the nature of their cognitive impairment.

Conflicting Understandings of the Best Interests of the Young Person

There are potential conflicts within the ethical considerations when engaging in research with vulnerable young people. The research must be in the best interests of the young person (United Nations Convention Rights of the Child (UNCRC), 1989). In the case of young people with PMLD, there will probably be several key people in their life, who may have different interpretations of their best interests. The principle that each child is entitled to express their own views and feelings (UNCRC, 1989) is at the centre of this research project, and this project assumes that everyone has the right and the capacity to give consent and to take part. The research outline was explained to those in a guardianship role prior to the research period.

Significant Relationships

Intellectual disability has an indisputable identity that is inherent in the individual (Rapley, 2004). The outcome of this research project may challenge the current perceptions and identity of some young people. This may impact on significant relationships in the young person's life, throwing into question the balance of power within those relationships. This ethical consideration needs to be acknowledged as part of this research project. It is hoped that the outcomes of this project are emancipatory for a marginalised, disenfranchised group of young people with PMLD, that it will enable them to enjoy personal autonomy and relationships of equal power and mutual respect. This type of relationship was evident when I observed a Music Therapy session during the pilot study. The therapist and the young person enjoyed making music together, taking turns to lead and to follow. The midday supervisor who was assisting the young person to eat her lunch was very respectful of the young person's

communication and dietary preferences. The young person reciprocated with animated smiles and laughter.

Participation Consent

Many of us give consent to things that we do not understand or know the outcome of, so this should not be an inhibiting factor (Iphofen, 2009). The consent to participate must be presented to the young person in a manner to which they can meaningfully respond. The young person has the right to withdraw and indications of the need to do this, however it may be expressed, must be respected (BERA 2018). It is good practice to have whatever method is used to indicate consent or withdrawal confirmed by a signed witness statement (Whyte, 2005). This signed statement will provide additional authentication to the consent given by the young person. It is acknowledged that young people with cognitive impairments have difficulty with prediction (Porter & Lacey, 2005). For consent to be meaningful for young people with PMLD, it is essential that a reliable method of demonstrating consent be used for each research activity in which they are involved. This method will be within their range of understanding and their comprehension of the task in which they are consenting to participate. To join in a music activity, the young person takes the percussion instrument offered and interacts with it, allowing someone to sit next to them. These are indications of consent (Simmons & Watson, 2014). The young people in the project were able to give consent to participate (Mental Capacity Act 2005: 3.1, 3.2) and to indicate if they wished to withdraw from a session (Wiles, 2013) in similar ways. The consent to participate is vital and this was achieved by the researcher becoming familiar with each individual's unique way of communicating (Wiles, 2013), with agreement indicated by a smile, reaching out to touch or a blow of breath. At the beginning of each interactive session the young person gave an individual form of consent to participate.

Headteachers can serve as gatekeepers (Wiles, 2013) within schools; therefore, it is vital to obtain their consent for their school to be involved with the project. The headteacher of each school gave consent for the participation of their school and, in particular, the identified young people. I met the parents of each young person, explained the research focus and answered any questions before requesting parental consent (Wiles, 2013). Each set of parents then signed an agreement for their son or

daughter to participate in the research. I explained the project to significant members of staff, answered questions, and each member of staff agreed to participate in the project (Wiles, 2013).

Confidentiality

It is usual for there to be several significant people closely involved in the life of a young person with PMLD, who know that person that would not normally be disclosed or shared, as deemed necessary for the welfare of the young person. This can raise ethical issues relating to confidentiality within the research process (Aldridge, 2007). People associated with the young person may think they have a right to know information that is confidential to the research process. My awareness of this potential issue, protected confidentiality in this respect. Throughout the research, the data were treated as confidential to the person who had consented to give those data, whether via interview or interactive session. All written records of or concerning the data were stored in a secure filing cabinet and all electronic data were stored on a password- protected iPad or PC.

3.6 Data Analysis

Introduction

I paid thorough attention throughout the data collection and the analysis to allow phenomena to emerge from the data. Essentially, analysis is an ongoing process between data collection and analysis (Bryant & Charmaz, 2007). This developmental relationship between the data collection and analysis allows patterns to emerge, so the researcher can focus on the developing patterns, without forcing them (Yin, 2014). Throughout the analysis process, it was vital to look very closely at the data being analysed (Urquhart, 2013). The fundamental principle of the analysis of qualitative data is that the analysis starts from the data rather than, as with quantitative data, with testing a hypothesis (Hammersley, 2008). The analysis is a process of searching for emerging trends within the data. The analysis of qualitative data can be overwhelming, challenging the researcher to question how they can make sense of all the data and present them in a meaningful way (Etherington, 2004). All data exist within social and institutional systems and these systems can create boundaries for the research data and subsequent analysis (Kushner, 2017). The current research was set within a national

educational system, a local implementation of that system and individual school systems. Individual family social systems also impacted the data. The systems exert procedures, experienced by the various participants in a wide variety of ways. Broader societal systems and values also provide a context and setting to the data and analysis of the data (Hammersley, 2008). However small the scale of the research, the analysis has the potential to challenge current systems and established values and constructs. This research process has challenged my previously held attitudes as a practitioner, as discussed further in Chapter Five – Discussion.

Analysis of Data

During data collection, a process of writing memos and notes was developed (Miles et al., 2014) in the form of observation notes for the interactive sessions and entries in my research journal.

The principles of Grounded Theory (see Section 3.3) analysis were applied to the data. I focused deeply on the data, trying as far as possible to eliminate prior knowledge and assumptions and allowing categories to emerge. This emergence was particularly evident in categories for all data sets except that relating to documentary evidence for each case study. The categories identified for the documentary evidence reflected the specific forms and processes recorded in the documents. The concepts identified may bring with them their preconceived notions (Urquhart, 2013). The identification of these categories could have been influenced by my prior knowledge and familiarity with these documents from my time as a headteacher. A researcher inevitably approaches the project with prior assumptions but these assumptions should be acknowledged and their impact minimised. The blinkers of the researcher must be removed (Hammersley, 2008). It was important to try to understand the data from the reality and meaning of the participants as they have the most thorough knowledge of their situation (Glaser, 2005).

When analysing data using coding methods, concepts are attached to the data. In the initial analysis of the interactive data for Harry, I used concepts with which I was familiar, in conducting the analysis from my perspective. The relationships between the various codes are important (Urquhart, 2013). For this project, the codes were set

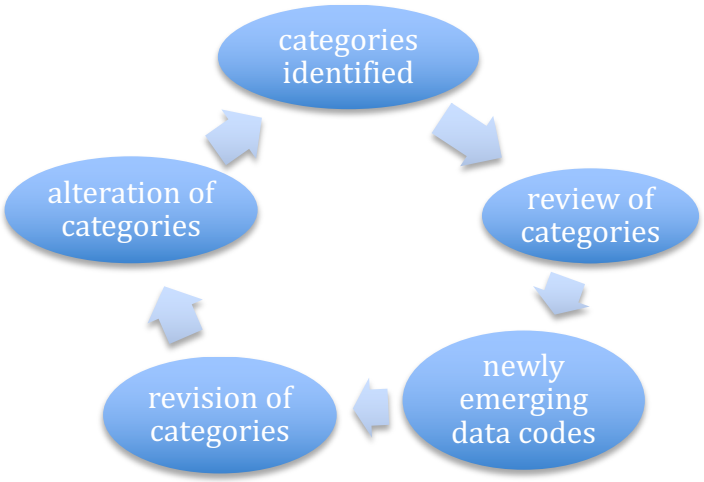
within categories. A category was an overarching term that included specific elements. It is important to pay particular attention to the naming of individual categories and how the categories relate to one another (Urquhart, 2013). The analysis of Katy's interactive activity identified a communication category that included sub-categories of communication touch, communication sounds and communication gestures (see Findings 4.4.1). Categories may overlap; for example, within the documentary evidence, the annual review report forms a category that includes elements of pupil progress, and the EHCP is a plan of the provision for a young person with SEN, including educational provision and objectives and containing comments about the young person's progress towards their educational objectives. The two categories can be seen as interrelated as both address aspects of educational progress. They are represented in the Education and Learning sections of the Findings (see Findings 4.2,4, 4.3.3, 4.4.2).

The emergence and identification of new or revised categories occurred through a repeated process of developing sub-categories from within the categories identified. It is this process of developing categories as the data develops that generates new ideas from the data. The researcher's ongoing reflections were recorded in the form of analytical memos included in the research journal. This process had an impact on the integrity of the data and subsequent analysis (Miles et al., 2014). The ongoing analysis generated a greater depth of appreciation and understanding, as demonstrated in the data concerning Katy. At the beginning of the data analysis, Katy's withdrawn approach was interpreted as a lack of understanding of the situation (see Findings 4.4.1). Later in the analysis, it became apparent that her withdrawal behaviour could indicate personal reflection (see Findings 4.4.6). The iterative style of the dynamic data collection process inevitably influences the data analysis. The process of analysis creates order from the data but that order is, inevitably, constantly shattered (Bryant & Charmaz, 2007): the categories are not fixed, the analysis is a process of questioning the data, possibly breaking patterns and reforming them in a different order. This occurs as different priorities appear within the data with the emergence of revised categories and relationships.

The process of identifying categories and sub-categories was often modified as the research analysis developed. The initial categories for Linda's documentary evidence

were revised to fit more specifically with the transition planning process but the revised categories did not align with the grouping prescribed in the document, so a new way of looking at the document emerged from the data. As the categories and sub-categories emerge, the process prompts a greater depth of analysis. The interactive data for Harry initially had emerging categories and sub-categories; then I realised that these categories had emerged from my perspective. The data was then reanalysed, allowing categories to emerge from Harry's perspective (see Findings 4.2.1). In revising categories and sub-categories, a system developed, drilling down into the depths of the data. This was an important process as it reflected and enhanced the depth of analysis required to understand the young people involved in this project.

Figure 3.6 The Cycle of Revision and Refinement of Data Analysis

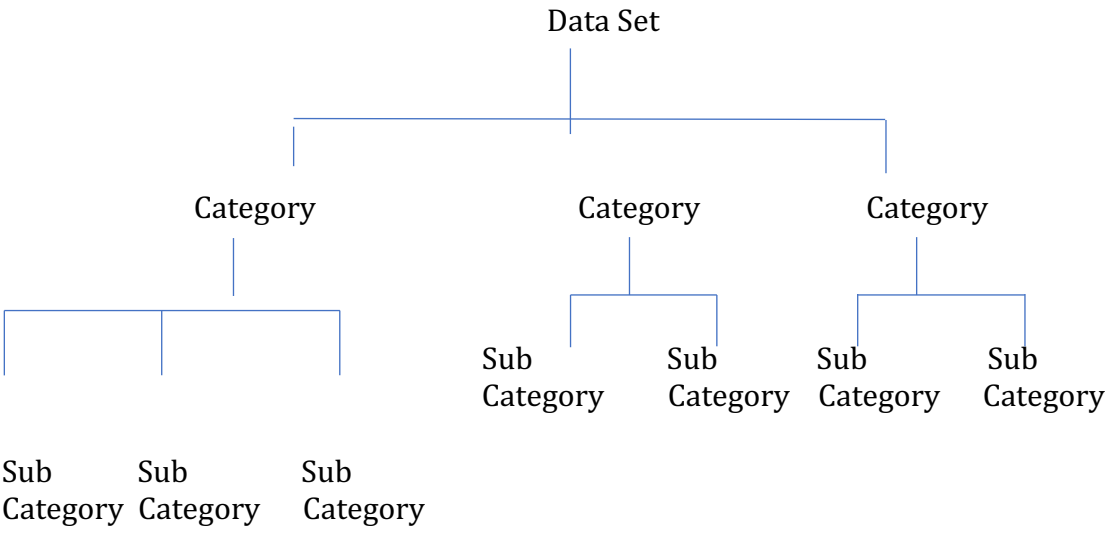


Throughout the data collection, it was important to try to see the participant experience. The development of the reflective journal provided a holistic record of the researcher's thoughts and experience throughout the research process. For example, within a few weeks of starting the collection of interactive data, I ask a rhetorical question in the journal, "How do I manage myself as a researcher?' This was in response to the realisation of my position as an outsider in the school community. Towards the end of the collection of interactive data, I comment that I am being pulled into the school culture, not maintaining my distance as a researcher. The journal became an integral part of the research process: it was a means of adding depth to the understanding of the experience of all participants. This is a heuristic approach based

on the work of Moustakas (1990). This heuristic approach was a principle applied within the analysis. The researcher's ongoing reflections in the form of analytical memos of the research process have an impact on the integrity of the data and subsequent analysis (Miles et al., 2014).

The process of analysing the data and revising the categories influenced my approach as the project evolved and developed. Harry was the first case study, and some changes were made (see Findings 4.1) as, following analysis for this data set, I realised that it was essential that categories should emerge from the data irrespective of whether or not these categories emerged in other data sets; some categories were common, others different (see Findings 4.2, 4.3, 4.4).

Figure 3.7 Analysis Structure Applied to the Analysis Process



The data sets for each case study were analysed separately. The content of each case study data is unique, with some similar and some specific elements, as discussed in more detail in Chapter Five – Discussion. The case studies were analysed in sequential order that aligned with the completion of data collection for the individual case studies of Harry, Linda and Katy.

From the close observation of the data and memo writing, connections began to emerge and form groups of similar data, thus forming categories. This can be seen in Linda's case study in which two categories – interactive school and interactive home – relate to

each other (see Findings 4.3.1). The two categories confirmed some convergence between the data for interactive school and home. The different environments did not affect Linda's interactive behaviour. This process of developing categories as the data develops generates new ideas.

As the interactive data was being collected, a process of writing memos and notes developed (Miles et al., 2014) in the form of observation notes for the interactive sessions and entries in my research journal. These were reviewed following each session and memos made that sometimes influenced the next interactive session. This was an ongoing, cumulative process throughout the interactive sessions and was broadly adhered to for each case study. In this way, categories were formed for each session and these were then analysed and modified to form an overall analysis at the end of each case study interactive session. Thus, the ongoing weekly analysis could be said to be formative, informing the following session, and the end of interactive analysis could be said to be summative in that it formed a final analysis of the interactive sessions in total.

The process of reflection recorded in the journal often indicated a slight change of approach for subsequent sessions. When Katy clearly indicated that she did not want to use the iPad but wanted to continue our playing games, I immediately changed my approach, listening to Katy. This reflexive process was not strictly part of the analysis process but influenced it. Initially, observation notes were used with a view to applying a coding process. I decided there was insufficient substantial data within each week's observation notes to develop categories and also noted this in the reflective journal. I decided to look at the notes weekly but to apply coding into categories and sub-categories at four- to six-week intervals. This provided more significant data to code.

The documentary and discussion/interview data were analysed at the end of the data collection period using Grounded Theory principles of categories and sub-categories. The categories and sub-categories for each case study and data set emerged as they were scrutinised and were each specific to the individual case study and data set. Data from the research journal was analysed in relation to each case study. It was decided to analyse data at the end of each case study; to have attempted to do this while the

journal was being written might have influenced the integrity of the journal. The journal needed to be a record of personal reflections on the research process. To attempt to analyse it while it was being written could have confused and compromised the honesty of the reflection which was crucial to this data set.
This reflexive and iterative approach to the analysis enabled me to identify the influence of my previous experiences. Although the data was approached in an as open-minded way as possible, it was viewed from the perspective of the researcher with experience of being a headteacher. These aspects are impossible to erase when looking at the data.

At the end of the analysis process, elements common to all three case studies were identified; Communication and Education and Learning Other contained elements evident in one or two of the case studies (Findings 4.2, 4.3, 4.4).

3.7 Validity of Data

Introduction

The validity of research is essentially dependent on the credibility of the research process applied. Qualitative research methods rely on the depth rather than the quantity of data and the credibility of the research is, therefore, dependent on the depth of data generated (Morrow, 2005). Thin data merely tells what has been observed whereas thick data provides intentionality, context inter-subjectivity and the deeper meaning of the subject and the context. Thick, rich data methods can provide insight into meaning and intentionality (Kushner, 2017). Qualitative data searches for patterns, explanations and suggestions of meaning (Miles et al., 2014).

Potential Risks

It was important to acknowledge potential threats to the validity of the data (Yin, 2014). Immersion in the culture of the research project when applying qualitative methods (Hammersley, 2008) can have potential risks to the objectivity of the data and subsequent analysis. The researcher brings knowledge of the situation yet remains outside the action of the research; this stance ensures objectivity in the researcher (Kushner, 2017) who needs to be constantly aware of their impact on the research process and its participants (Morrow, 2005). The participants' perceptions of the

researcher can influence the way participants react and respond in the research situation. The research is vulnerable to alternative interpretations. This project is based on principles of social justice and emancipation (see Introduction to this chapter). There are various constructs of disability.

Integrity of Data

Honesty is essential for the integrity of the research process and the data generated. The scope and future applications of the outcomes must be acknowledged as an integral feature of the research process and the meaning of the data (Morrow, 2005). In the case of the current research, the processes may be repeatable but generalisation is unlikely due the individuality of each young person and their circumstances (Morrow, 2005). It is important to collect sufficient rich data as appropriate to the focus of the research, taking into account the context of the research and other influential factors (Charmaz, 2014).

A deep understanding of the data is vital. Detailed understanding can be achieved through many aspects of the project: detailed descriptions of circumstances and situations; what these circumstances mean to the people involved and the inter-personal relationships; how these explain actions and bring meaning to the data (Miles et al., 2014).

The data is held in constant review by the repetition of processes, for example, interactive sessions and the observations of these sessions. The repeated review and checking of the data give them authenticity (Bryant & Charmaz, 2007).

Endorsement of the Research Process

Validation of research projects can be made by the research community within which the project sits (Yin, 2014). The current research is located within a small field of research and practitioner activity. The core principles of inclusivity and participation for young people build upon previous work (Nind, 2014) and case study models have been used in other research with young people with PMLD (Simmons & Watson, 2014). Intensive Interaction has been developed as an alternative method of communication

with young people with PMLD (Hewett et al., 2012). The current project incorporates processes that have been applied by other people working and researching in the field.

The participants in the research are with the young people daily in various circumstances; their endorsement of the research activity can provide additional validity (Hammersley, 2008) and several examples of this were seen during the current research.

In one of the intensive interaction sessions, Katy refused to use an iPad when it was offered as part of the session. The research assistant, who is also a teaching assistant working with Katy made the following comment:

> Katy is refusing to use the iPad in class. I think she is bored with it. 9.5.2016

A similar comment was made regarding Linda's use of a communication aid:

> Interesting how Linda keeps words at the top of the communication aid in this session. She usually deletes them. 16.5.2016

Linda's mother also endorsed the communication within the interactive sessions, making the following comment during one interactive session:

> I have only seen Linda like that with one other person. Sometimes we have exchanges such as that when we are mucking about when she is having a bath. 22.8.2016

These comments offer congruence with the research process and, thus, endorse the validity of the data. The thickness and richness of the data will be explored in greater depth in the following chapter about the findings.

3.8 Concluding Comments

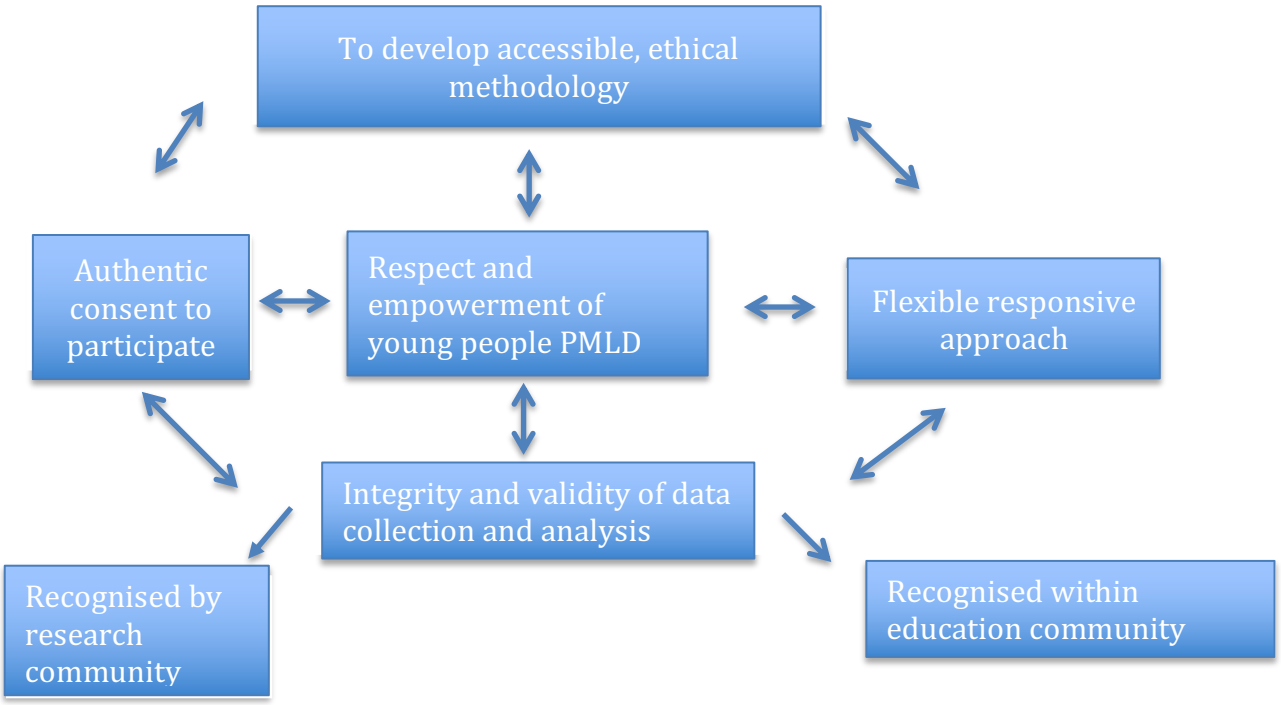
Continuous Themes

Certain themes run throughout the methodology. At the heart is the desire to create a methodology that is respectful and empowering for the young people, the subjects of this study. To achieve that, it is necessary to develop an innovative, accessible

methodology that discerns the 'voice' of each young person and is flexible and responsive to the young people and their situation.

Categories were identified throughout the research process; they emerged from the data and were specific to the data collected for this project. Themes are ongoing issues that continue to need to be investigated and developed; they are broad issues that are not specific to this project, although they are integral to it.

Figure: 3.8 Continuous Themes Throughout the Project



The issues identified in the diagram above run throughout the research project. They are addressed but not resolved within this project and are very much part of a work in progress. This project and the methods used in it are part of a journey to provide young people with an authentic voice in the transition and the research processes.

CHAPTER FOUR

FINDINGS

4.1 Introduction

Every human being is unique but young people with PMLD (see Literature Review 2.4) particularly so, as each has a unique combination of difficulties (Simmons & Watson, 2014). The complexity of these difficulties can create barriers for the young person and for those around them. The findings are the result of an attempt to understand the barriers and to investigate methods of trying to minimise and possibly eliminate them. As each young person is unique, it is necessary for the approach to each young person equally to be unique.

Throughout the project, a responsive approach was taken to the emerging data associated with each young person (see Methodology 3.3) and, in particular, the data generated through intensive interaction, in conversations with significant people and my reflections on the research process. The findings are influenced by the methods used. In this project, the use of Intensive Interaction as a research tool influenced the data collection and, subsequently, the findings (see Methodology 3.4).

There is a common exploratory and innovative approach to the case studies. The focus is to explore new ways of working with young people with PMLD at the time of post-school transition. The exploratory, reflective nature of the research design meant that slight modifications were made throughout the research process and influenced the findings (see Methodology 3.1). Emerging phenomena throughout the data collection created an ongoing dialogue between the data and the analysis. The various social, institutional and family settings were considered. All these elements influenced the findings (see Methodology3.6.).

Each young person is unique, and each had individual life circumstances. This provided a range of circumstances and data relating to young people with PMLD at the time of transition from school. From my experience as a practitioner (see Introduction 1.2.), I

know that the issues raised by each case study have relevance to a wide range of young people with PMLD. The different case studies and the data generated are strengths of the project because they provide a diverse range of material that may have been missed if uniform, methodological approaches had been used. Linda's case study included data collection in the family home and at Linda's post-school placement at college. Although not in the original project plan, the opportunity arose to continue work with Linda after she had left school and, thus, the interactive sessions continued at Linda's home and I was able to follow up with post-school transition visits to the college. This revealed some very relevant practical issues that are important to the transition process.

In contrast, I was unable to have a discussion with Katy's parents at the end of the project due to a variety of circumstances within Katy's family. Katy herself was very ill and spent time in hospital which naturally raised anxieties for the family and they withdrew into themselves for a significant period. Following this, it was difficult for the family to let Katy return to school as they were anxious about her health and wellbeing. At the same time, Katy's parents were experiencing difficulties in their own relationship leading to their separation. It was simply not appropriate to approach the family to discuss issues related to the research project. Yet this situation is authentic and must be respected. Having a child with PMLD can put significant strain on the relationship between the child's parents, a phenomenon that I regularly witnessed as a practitioner.

As noted in Chapter Two, young people with PMLD experience communication difficulties, a range of health-related problems, physical disabilities and, consequently, the involvement of multiple professionals in their lives. They are dependent on other people's support to enable them to engage with the community. In summary, while each case study is unique, together they present a range of phenomena that are illustrative of the type of issues experienced by young people with PMLD

The combination of a reflexive approach to the emerging data and the individual circumstances has resulted in three case studies that are characteristically different from one another but from which certain shared themes can be drawn. This chapter will go on to present the analysis of the data in these two phases.

Analysis of the data for each case study revealed a variety of themes; a few common to all three case studies, several appearing in two and others specific to individual case studies. Despite the common themes, slightly different features are revealed in each case study. This is to be expected as each case study concerns an individual young person and those people who are associated with that young person. The application of Grounded Theory principles encourages the emergence of themes from the data but this process is not prescriptive. The person conducting the analysis must immerse themselves in the data to enable the data to speak independently of preconceptions. It would be tempting to put similar elements together for the sake of uniformity but that would not sit within the spirit of the project and research methodology. For example, within Katy's findings, a theme of thoughtfulness emerged while Harry's data revealed themes of emotion and empowerment. While it may be possible to combine the essence of these themes, to do so would not reflect the particular individuality of each case study or respect the individual integrity of the data.

Two themes common to all case studies were Education and Learning, and Communication. In each case study, these two themes have a different emphasis and interpretation. Once again, this is appropriate to the methodology of the project. The different issues raised by an individual case study within the common theme demonstrate the breadth of the themes, and these will be discussed in detail in Chapters Five and Six.

Throughout the findings for each of the case studies, particular issues arise which will be discussed in detail in Chapter Five. The issues identified in each case study will be identified in the introduction to each case study.

Introduction to Case Studies

The study includes three case studies of young people with PMLD (see Introduction 1.9), each of whom is at a different stage of transition planning in Years 9, 10 and 11 respectively. All the young people attended special schools in the same county; two attended the same school and one a school in a different part of the county. The case studies enabled the collection and analysis of deep, thick data (see Methodology 3.3).

Each young person has a combination of disabilities that will be described in more detail in the following sections.

4.2 Harry

Harry is a young man with PMLD. He has very limited communication through limited facial expression, vocalisation (G57) and gesture but very often chooses not to use even these limited forms of communication. Harry often chooses to be in his own world in his wheelchair with his head hung down. To have any communication with Harry can be very challenging and people may give up or simply guess what he wants or needs. Harry has significant health issues: he experiences epileptic seizures (G16), is a wheelchair user and has suffered a couple of strokes that have further restricted his independent movement. Following one stroke, Harry required a tracheostomy to help him to breathe. This has subsequently been removed.

Harry – Specific Findings

Six themes emerged from the analysis of data associated with Harry:

- communication
- education and learning
- health
- empowerment
- emotion
- perceptions of Harry

These themes occurred throughout the data sets, Intensive Interaction sessions, discussions with significant people in Harry's life, documentary evidence and researcher reflections. The emphasis of the themes within the data sets varied.

The following broad issues arose from the findings:

- Communication
- Attitudes to and perceptions of Harry
- School ethos
- Parental inclusion

These issues will be discussed in detail in Chapter Five.

4.2.1 Communication

The communication theme unfolded with two strands: the communication that Harry revealed and used during the interactive sessions, and the communication that Harry was taught in various situations. There was some overlap. Eye contact was noted as of significance in Harry's annual review report and, in one annual review report, listening was noted as being important.

Annual Review Report 2015:

Make eye contact on request
More willing to respond to requests
Listens well
Press switch independently (G 51) with encouragement
Use iPad
Posture less slumped
Able to grasp and release an object

This report includes references to eye contact and listening. Listening was not particularly noted in the interactive notes; however, it was implied in many of the actions that Harry made in the sessions. These two aspects of communication were revealed in the interactive sessions and will be discussed in more detail later in this section.

Achievements noted in Harry's report in 2016:

Good eye contact
Able to use a switch for single word responses
Uses symbols (G52) correctly to identify correct response from a choice of two
Makes marks on paper
Personal Progress Achievement award ASDAN

This report just notes eye contact, also noted as a form of communication in the interactive sessions.

The notes from the annual review reports above refer to aspects of communication that Harry has been taught and his response to these. This communication is a

predominantly functional language, for example, touching a switch or symbol to indicate that he wants a drink. The language which he is taught to use is prescribed in that it comprises individual words that professionals have decided that it would be useful for him to learn, as indicated in the learning intentions. This primarily involves the use of Makaton communication symbols and specifically designed communication switches. As indicated in the report, Harry is required to press the switch or touch a symbol in order to indicate a preference.

Future education delivery intentions regarding communication and EHCP outcomes focus on Harry continuing to develop skills related to switches and symbols, as seen in the delivery intentions included in his annual review reports in 2015 and 2016.

> To use a switch to make choices. To use a symbol on a switch
> To explore objects. To explore temperature hot/cold
> To work harder in physiotherapy

Similar points were noted in Harry's EHCP outcomes for the same period.

> Objective from Statement of SEN 'to develop independence in his self-help skills'. (G41)
> Outcome in EHCP 'use either switches or symbols to make consistent choices in order to demonstrate his cognitive abilities'.

The interactive sessions revealed other aspects of communication that emanate from the individual, in particular, emotional aspects that are important to note, such as how Harry revealed his own sense of self-worth and empowerment. Harry's complex and multiple disabilities influence how people perceive and react to him and these perceptions may have an impact on the personal autonomy that he is encouraged to exercise. At the beginning of the interactive sessions, Harry was shutting people out, refusing to communicate with them, closing his eyes and hanging his head. Gradually, Harry began to respond to Sue's attention. The notes from the Intensive Interaction sessions show when Harry began to look at Sue. Although they do not describe direct eye contact, they indicate Harry's interest in Sue.

> I partially closed my eyes, bowed my head and rocked in my chair. Harry looked at me fleetingly out of the corner of his eye. (Notes 22 April 2016)

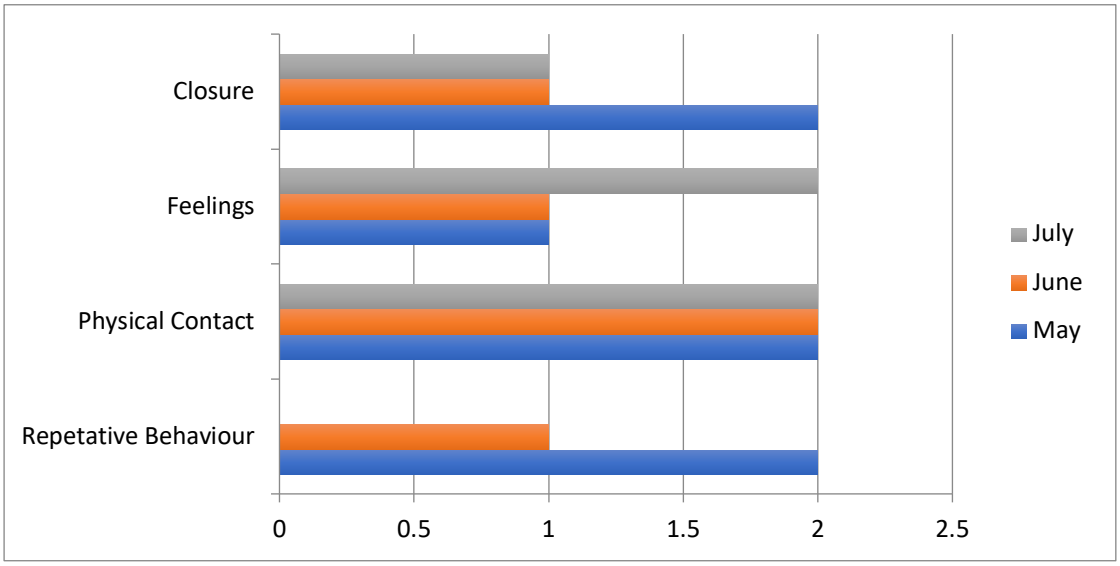
This is similar to the communication activity of eye contact noted in the annual review reports.

Other aspects of communication that were revealed during the Intensive Interaction sessions involved Harry communicating using the skills that he had, such as laughing and smiling, as seen in the notes below.

> Harry smiling and laughing (Notes 2 June 2017)

During the period of the interactive sessions, Harry's communication increased, shown in Figure 4.1.

Figure 4.1 Graph to Demonstrate Frequency of Different Communication used by Harry



Harry's desire for physical contact appears to be consistent throughout the interactive sessions. As the sessions developed, Harry appeared to be making fewer attempts to shut down from the session (closure) and was displaying more emotions. Overall, Harry's confidence in his own communication skills developed in the course of the interactive sessions. These observations were recorded in the observation notes below.

> Harry throwing his head back, laughing, thigh slapping, whole body shaking (Notes 18 July 2017)

It must be acknowledged that Harry's communication in the interactive sessions is open to interpretation. It is important to remember that everyone's communication is dependent on the interpretation of the receiver. Staff who work with Harry stated that they were often uncertain of the meaning of Harry's communication, as demonstrated below.

> When I am in the toilet with Harry, he giggles. I am not sure what that means. (Notes TA1. 5 July 2016)

When the analysis of Harry's interactive data was complete, I realised that it had been conducted through the lens of the researcher, yet the purpose of the research was to investigate the ability of young people with PMLD to contribute to their own post-school transition planning process. In analysing the data through the researcher's lens, there was the potential to apply a biased interpretation similar to the people conducting the transition planning by not truly trying to see through the lens of the young person. As a consequence of my reflexive thoughts as a researcher (Kamler & Thomson, 2014), it was decided to return to the data, examine the records of the interactive sessions and try to represent them from Harry's perspective. This was a process of looking for meaning from Harry's perspective which may differ from how I, as the researcher, had interpreted it (see Findings 3.6). The notes below illustrate activity as it could be understood from Harry's perspective. The analysis of the data from Harry's perspective formed a category with various sub-categories. The initial analysis identified a sub-category of repetitive behaviour when Harry repeatedly did the same thing. When seen from Harry's perspective, these behaviours can be seen to be enjoyable. He is choosing to do what he wants to do, his own thing.

Rocking from side to side. (Notes 2 June 2016)
Nodding head from side to side (Notes 9 June 2016)

A sub-category of mutual contact was identified in the analysis made from the researcher's perspective. When seen from Harry's perspective, these are simply times when Harry wants to attract Sue's attention. It is often difficult for young people with PMLD to attract attention to themselves, although this is taken for granted by many people without the same level of disability. This will be discussed in more detail in Chapter Five.

Put right hand out towards Sue (26.5.2016)
Grab hold of Sue's hand at beginning of session (Notes 28.6.2016)

The researcher analysis identified a sub-category of showing emotion. When seen through Harry's eyes, this becomes sharing.

Pass toy to Sue (Notes 28.6.2016)

Closure was identified as a sub-category from the researcher perspective but, when considered from Harry's perspective, it may indicate that Harry is becoming bored or taking some time out from the activity, a subtle but important difference in interpretation: 'I am getting fed up/bored'. A category emerged from Harry's perspective that demonstrated his potential thought processes, as demonstrated in the notes below.

Looking beyond Sue and to the side of her (Notes 2.6.2016)
Looking out of the window (Notes 17.6.2016)

I am not sure; these were times when it seemed that Harry was thinking about things, perhaps working out what to do next. This will be discussed in more detail in Chapter Five.

Look either side of Sue then continue to hold her hand (Notes 2.62016)
Looking out of the window and then continue to play with Sue's fingers (Notes 17.6.2016)

The interactive dialogue was initiated by copying behaviours. Harry did not resist this and gradually began to engage. He was demonstrating that he was happy for his behaviours to be copied and may have felt that another person was entering into an activity that he enjoyed. This would have enabled the relationship to develop with confidence to explore new avenues of communication.

The comparison of the analysis perspectives raises some interesting issues as to whether they relate to one another, whether they demonstrate difference or similarity of meaning (see Figure 4.2).

Figure 4.2 Comparative Analysis

	Harry Analysis		**Sue Analysis**
1.	Attract Attention	⟷	Mutual contact/engagement
2.	Getting fed up/bored	⟷	Closure
3.	Sharing	⟷	Showing emotion
4.	Doing my own thing	⟷	Repetitive behaviours
5	I am not sure		

Point 2 indicates a similarity of meaning: Harry is demonstrating that he is feeling bored and the researcher analysis interprets this as closure. The effect of both interpretations is that the activity is no longer interesting; it needs to end. Point 3 also illustrates similar meanings. Harry is demonstrating that he wants to share something and the researcher's analysis sees this as showing emotion. To want to share something with another person can be seen as sharing at an emotional level. Point 1 demonstrates similar elements but with subtle differences. If Harry is trying to attract attention, he is demonstrating that he is present and wants to interact. The researcher's interpretation potentially shows the researcher's subliminal bias. The researcher felt excluded by Harry at the beginning of the interactive sessions. When he became more demonstrative, this reinforced the researcher's sense of self and was rewarding for her. Thus, to feel that Harry wanted mutual contact was affirming for the researcher, as the interpretation illustrates. Point 4 demonstrates a discrepancy in the two interpretations of the data. From the researcher's perspective, these are repetitive behaviours but, when seen from Harry's perspective, they become Harry 'doing his own thing'. I know from professional experience that many young people with PMLD choose to do particular activities over and over again to amuse or stimulate themselves. Harry's rocking activity is an example of such activity. Repetitive behaviour carries with it a tone of subtle judgement towards the activity, an example of potential bias from the researcher reflecting her professional background in education. Harry has a unique activity, 'I am not sure', not identified in the researcher's sub-categories. This demonstrates an attitude of reflective thought that is seldom acknowledged within the school setting. This type of thought comes from a deeper place and is common to us all, including young people with PMLD and will be discussed in more detail in Chapter Five.

It is important to be mindful of the different perspectives of the emergent data to maintain an open mind (Gibson & Hartman, 2014). In this instance, some of the finer details of the communication would have been missed had only one perspective been applied.

4.2.2 Education and Learning

The data relating to education and learning revealed educational aspects that predominantly referred to educational provision, planning and opportunity. Learning

emerged as those elements which Harry has demonstrated that he has learned. Activities and opinions emerge relating to these broad aspects, what they are and what they mean for Harry and those people involved in his life. The researcher's reflections reveal the impact of the researcher's previous experience in education on the research process when she is involved with Harry.

As the interactive sessions developed, Harry demonstrated that he had learned that he could communicate within the interactive sessions, as can be seen in the notes below.

Harry looked at Sue, then looked away. Repeated this and then put his hands up.(observation notes 2.6.2016).
Harry repeatedly touched Sue's fingers and gave lots of eye contact to Sue.(Observation notes 17.6.2016)

Harry demonstrated that he had learned how to develop relationships as demonstrated below, showing significant learning from Harry's initial attitude of bowing his head, resisting any interaction.

Put Sue's hand on mine (Harry's)(Notes 28.6.2016)

Within the annual review, Harry's learning achievements in 2015 and 2016 are noted.

Make eye contact on request
More willing to respond to requests
Listens well
Press switch independently (G 51) with encouragement
Use iPad
Posture less slumped
Able to grasp and release an object

Good eye contact
Able to use a switch for single word responses
Uses symbols (G52) correctly to identify correct response from a choice of two
Makes marks on paper
Personal Progress Achievement award ASDAN

Learning intentions for the future are noted for 2015 and 2016.

To use a switch to make choices
To use a symbol on a switch
To explore objects
To explore temperature hot/cold
To work harder in physiotherapy

Discussions with significant people in Harry's life at school revealed varying understandings and views of Harry's learning and learning opportunities, illustrated in the notes below.

I am not sure if I understand Harry (Notes TA2. 5.5.2016)
I am frustrated with the class teacher (Notes TA2. 7.7.2016)
I wish the staff team could work together to support Harry to provide necessary support so he can participate fully in his education (Notes T. 12.9.2018).

The use of photos and switches are important to help Harry to communicate.(Notes T. 7.11.2016)
I am beginning to understand need to break down tasks into small steps for Harry (Notes TA1. 5.7.2106)
Harry is being pushed too much. (Notes TA2 7.7.2106)

The lack of shared educational aims and understanding has created conflict within the class team. In the transfer document from Statement to EHCP, Harry's mother makes the comments below, indicating her concern that Harry's health issues do not interfere disproportionately with his education.

Harry's mother said that his scoliosis surgery and tracheostomy (G55) reversal to be completed by end of school year. She hopes these will be successful and that Harry will not need more extended time off school. That he will enjoy life more and be more physically active (Transfer document 3.3.2015).

Harry's mother wanted to talk about Harry's leisure activities.

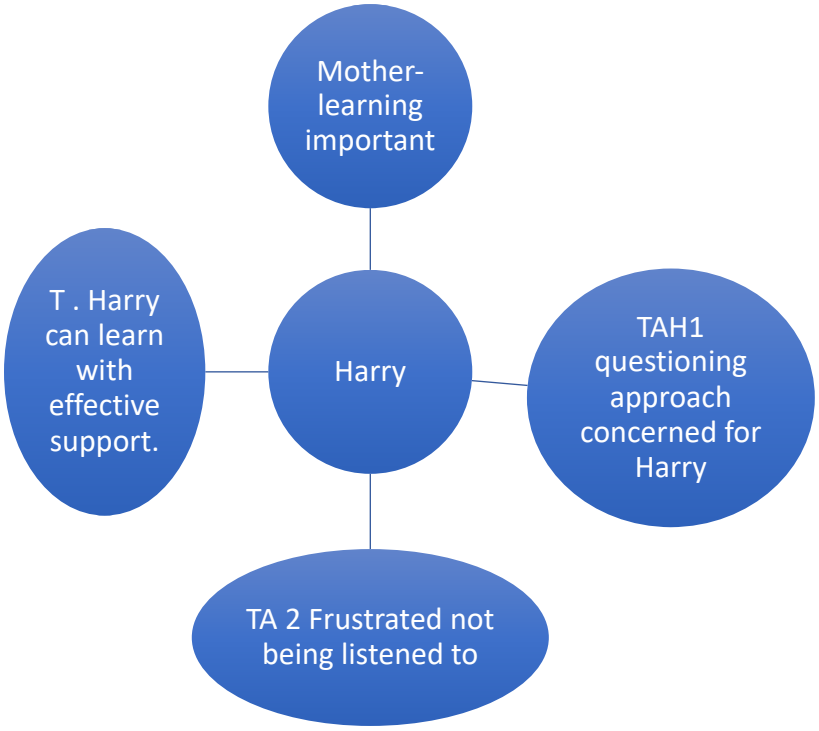
Harry enjoys watching TV and DVDs. He enjoys going for walks in his wheelchair and going to the cinema. Harry eats really well at home and enjoys a roast dinner.

These activities could be included in Harry's learning opportunities at school but there is no indication that this is the case from the data. It is possible to conclude that communication between school and Harry's mother could be more effective, particularly as Harry's mother did not know who his teacher would be in September when I spoke to her in the middle of August.

I don't know who Harry's teacher is going to be next year (Mum 12.8.2016)

Opinions differed regarding Harry's engagement with education. Harry's mother was keen for him to learn and seemed to trust the school to provide those opportunities. Within the school setting, there was a divergence of opinion and attitude of which Harry's mother was unaware. All these elements have an impact on Harry's learning engagement, as shown in Figure 4.3.

Figure 4.3 Summary of the Varying Views Regarding Harry's Learning and Education.



In this research project, I was mindful of my previous role as headteacher of a special school. Through the reflective journal, I noted examples of my previous experience as a teacher on the research process and how this can be seen in my attitude to learning and education, as seen in the extracts below.

> I need results. I am in a dilemma because I do not know where this interactive activity is leading. No. I must remember the purpose of the research is to give complete autonomy to the young person. (Notes 26.5.2016)

The hidden ethos in this comment is that education needs to include identifiable progress and direction.

The following reflections regarding the researcher's previous role as a headteacher show the inherent pressure to strive for constant identifiable improvement.

> I bring skills from my role as headteacher, experience from my previous role that are helpful but I am making a completely different point of contact with the parent. As a headteacher my role was to lead and motivate the school community, constantly striving to improve and make things better. To promote the school. As a researcher I have no agenda simply to find out about Harry and his relationships. To seek to understand Harry. (10.5.2016)

Similar questions were raised regarding the relationship between education and research, particularly noting the inherent pressure in school situations. This will be discussed further in Chapter Five.

> The researcher sees the need for the research. Do all the others involved with Harry see that need. It is difficult when there is so much pressure to meet the daily demands of the job, whatever it is in the school (24.6.2016)

4.2.3 Health

Issues relating to Harry's health were evident throughout the data. They varied but related predominantly to Harry's significant physical health issues.

Harry's mother had a very pragmatic attitude to Harry's health. She acknowledged its impacts and did not want it to inhibit Harry's opportunities in life. She spoke of Harry's health issues simply as matters needing to be addressed, adopting a factual tone, as demonstrated in the notes below.

> Harry had a stroke in 2009, he then had a tracheostomy fitted (Notes 10.5.2009)
> Harry part of his throat re-constructed following tracheostomy (Notes 10.5.2016)
> Harry had complicated back surgery in August 2015 (Notes 10.5.2016)

In contrast to Harry's mother, the TAs spoke with concern of Harry's health and general well-being, as the notes below indicate.

> Harry gets very tired. (Notes 5.7.2106)
> I have known Harry since he was in Nursery. I have watched him deteriorate. (Notes 5.7.2016)
> I can see the impact of Harry's health over a long time. (Notes 5.7.2016)

Harry's teacher seemed to adopt a middle ground, acknowledging Harry's health problems but wanting them to be overcome to facilitate his access to education, as the comments below indicate.

> Ideally education, care and health should work as a triangle of mutual support. Sometimes I think that this can be misinterpreted, particularly by TAs, and the balance can be dominated by care. (Notes 7.7.2016)

The teacher expressed a degree of frustration around the attention on Harry's health and care. Issues relating to Harry's health were particularly noted in his annual review reports, as shown below, with particular issues relating to Harry's health and how they may impact his school attendance detailed in 2015. His school attendance is closely monitored. Harry's absence is authorised because of his health issues but it will impact on his progress.

> Tracheostomy (G 55),Breathing difficulties, mobility and walking
> Authorised absence from school

Similar health issues were identified in the 2016 Report:

> Various issues relating to surgery Authorised absence from school 142

Harry's case involved school staff and health staff working together, sharing availability of appropriate equipment and personnel resources to enable him to access the school curriculum and community resources, as noted in the comments below.

> Harry's strength and stamina will be built up with guidance from the physiotherapist. This will happen every day. Will be the responsibility of the teacher or TA. (Transfer meeting 3.3.2015).

> Harry will have a specialist TA to support his medical needs in school while he has a tracheostomy (Transfer meeting 3.3.2015).

Harry has many complex chronic health (G12) issues that impact his life in general and his education in particular, including nocturnal epileptic (G16) seizures that can affect his alertness during his education in the day and very poor muscle control requiring great effort on his part to hold his head up. These are examples of the duality of education and health. Harry needs the correct seating provided through physiotherapy

to maximise his capacity to hold his head up. A stimulating educational environment will also motivate him in this regard.

Physical health issues emerged as being of the greatest importance to those involved with Harry. There was no mention of Harry's mental health although, in the interactive sessions, he displayed certain behaviours that could be interpreted as being indicative of mental health issues. At the beginning of the interactive sessions, Harry was very withdrawn and recoiled from any form of contact with me, as recorded in my research notes below.

> When I first met Harry he closed his eyes, bowed his head and began rocking in his chair. (Notes 22.4.2016)

This behaviour can be interpreted as that of someone who is very introverted and lacking in confidence and social skills.

> Rocking from side to side. (Notes 2.6.2016)
> Nodding head from side to side (Notes 9.6.2016)

The comment above notes that Harry is rocking in his chair. This behaviour was exhibited later in the sessions and could be interpreted as a sign of depression or anxiety. Harry's mental health is not mentioned in any of the documentation. This type of behaviour can also be interpreted as self-stimulatory, possibly an attempt for Harry to communicate with himself in some way because he is unable to experience fulfilling communication with other people. This will be discussed in more detail in Chapter Five.

4.2.4 Empowerment

Harry's complex and multiple disabilities influence the way people perceive and react to him. These perceptions may have an impact on the personal autonomy that Harry is encouraged to exercise. The findings in this section explore the effect of these various perceptions. At the beginning of the interactive sessions, Harry was shutting people out, as explained in the previous Communication and Health themes. As the interactive sessions developed, Harry gradually began to initiate contact.

> Harry looked at Sue, then looked away. Repeated this and then put his hands up. (Observation notes 2.6.2016).
> Harry repeatedly touched Sue's fingers and gave lots of eye contact to Sue. (Observation notes 17.6.2016)

Harry began to initiate sharing objects with me. Through the change in his attitude, it is possible to see him taking more control of his environment and his relationship with the interactive partner. These are demonstrations of Harry experiencing and exercising empowerment.

At home, Harry experiences a degree of empowerment. His mother has a clear idea of what he enjoys and enables him to participate in those activities. Harry's mother wanted to talk about his leisure activities as shown below.

Harry has a hot tub in the garden; he loves going in it (10.5.2106)
Harry loves watching fish swimming round in the fish tank (12.8.2016)

Harry's attitude at home was noted in the researcher's reflective journal after a visit to Harry's home.

Harry seems much more relaxed at home than when I have seen him at school. (Notes 12.8.2016)

The attitudes of the school staff to Harry were mixed. His teacher expressed a degree of frustration that attention to Harry's health and care, particularly by TAs, was potentially reducing his access to educational opportunities, as indicated by comments included in the Health theme. The TAs demonstrated a caring, almost protective, attitude to Harry's health needs, as indicated below.

I can see the impact of Harry's health over a long time. (Notes 5.7.2016)

Within the same classroom, there were examples of different approaches to Harry – both an open-minded questioning approach and a more 'expert' controlling approach – as indicated in the comments below.

We know Harry best (Notes TA2 7.7.2016)

I am not sure if I understand Harry (Notes TA2. 5.5.2016)

This mixture of attitudes towards Harry at school may have a confusing impact on his sense of empowerment.

It must be noted that Harry did not attend the annual review or transition planning meetings associated with him. The impact of this will be discussed in Chapter Five,

along with further issues arising from the theme of empowerment, including the impact of Harry's health and how this influences his autonomy, and the impact of other people's perceptions of Harry and how this may liberate or confine him.

4.2.5 Emotion

Harry demonstrates a range of emotions that form an alternative means of communication when he has a limited ability to use more traditional methods. The emotions he shows range from being withdrawn or depressed to being happy.

> When I first met Harry he closed his eyes, bowed his head and began rocking in his chair. (Notes 22.4.2016)

On other occasions, Harry appeared happy and outgoing.

> Harry throwing his head back, laughing, thigh slapping, whole body shaking (Notes 18.7.2017)

Harry reached out and wanted to share things when he was happy.

> Pass toy to Sue (Notes 28.6.2016)
> Put Sue's hand on mine (Notes 28.6.2016)

When Harry was bored with an activity, he was able to indicate his feelings, as shown in the note below.

> Looking beyond Sue and to the side of her (Notes 2.6.2016)
> Looking out of the window (Notes 17.6.2016)

It is difficult to interpret Harry's emotions. The interpretation depends on the lens through which it is made. The note below could be interpreted as Harry feeling bored or, when interpreted from a different perspective, it could be concluded that Harry is feeling uncertain because he is looking away and then returning to focus on me, as mentioned in the communication theme (Section 4.2.1).

> Look either side of Sue then continue to hold her hand (Notes 2.6.2016)
> Looking out of the window and then continue to play with Sue's fingers (Notes 17.6.2016)

At home, an alternative view of Harry's emotions is revealed. His mother talks about the things that Harry loves at home, indicating a strong emotional attachment to aspects of his life at home.

> Harry loves cats. He has 5 at home (10.5.2016)

Following a visit to Harry at home, the following note was made in the research journal.

> Harry seems much more relaxed at home than when I have seen him in school.

This is an indication of Harry's emotional state and may mean that he feels anxious when he is at school.

The annual review documentation contains references to Harry's emotional reaction to various activities.

> Look bewildered when switch changed from saying bonjour to hello
> Interested in packaging from box
> Sit whilst being read to
> Loves the light room especially different lights
> Interactive cooking sessions
> Looks at different instruments when given them
> Scrunches leaves when given them.

The record of Harry's reactions above demonstrates a variety of emotional responses: bewilderment, enjoyment of particular activities and tactile interest in particular objects.

Although there is a relatively small amount of data within the emotional theme, it represents a significant strand of response and reveals aspects of Harry's personality which are relevant to an overall understanding of him.

4.2.6 Perceptions of Harry

The approach to working with Harry during the interactive sessions was to play a facilitative, respectful role. Through the process of reflecting on the interactive sessions, I became aware of reactions and motivations that affected my perceptions of them and Harry. An extract from the reflective journal illustrates this point.

> I need results. I am in a dilemma because I do not know where this interactive activity is leading. No. I must remember the purpose of the research is to give complete autonomy to the young person. (Notes 26.5.2016)

At school, staff tended to perceive a young person with significant problems and responded to this perception in a variety of ways. Some staff showed uncertainty at

times. They may have found Harry's problems challenging, which may have caused them to lack confidence when spending time with him.

> When I am in the toilet with Harry, he giggles. I am not sure what that means. (Notes TA1. 5.7.2016)

Other staff were almost over-confident in their perceptions of Harry, seeing themselves as experts on him. This demonstrates a perception of Harry as a well-known quantity needing particular expert understanding.

> We know Harry best (Notes TA2 7.7.2016)

Some staff are protective of Harry.

> Harry is being pushed too much. (Notes TA2 7.7.2106)

The teacher saw Harry as a young man who could achieve.

> I want Harry to achieve and develop and I am sure he can.

At home, Harry's mother exhibited a very normal perception of Harry as her son. She acknowledged his health issues but did not see them as an insurmountable obstacle that should prevent him from participating in life and activities.

> Harry enjoys watching TV and DVDs. He enjoys going for walks in his wheelchair and going to the cinema. Harry eats really well at home and enjoys a roast dinner.

The documentary evidence demonstrated a contrast in perceptions of Harry: the school perceived him as a young person who needed to be supported and encouraged to achieve while his mother acknowledged the need for him to achieve but primarily wanted him to overcome his health issues so that he could enjoy his life.

The researcher's perceptions of Harry reflected her professional background in education although, as a researcher, there was no particular expectation as to how to perceive Harry. The perceptions of other people with particular roles in Harry's life may have been influenced by their role. Whatever the perceptions of Harry, they affect how people relate to Harry which, in turn, affects Harry particularly because of his severe communication difficulties.

4.2.7 Concluding Comments – Harry Case Study

In the school setting, it emerged that Harry often chose to self-isolate, particularly from staff with whom he did not want to communicate. His behaviour towards them could be described as passive-aggressive in some instances. Through the interactive sessions, Harry showed that he enjoyed interaction on his own terms and enjoyed sharing with another person. At home, Harry enjoyed a varied life with interaction with his wider family and community and liked participating in particular activities with his family. His home life seemed separate from his school life and this was apparent in his different attitude in the two settings. Harry's health issues are significant and impact his life.

4.3 Linda

Linda is a young lady with Downs Syndrome (G14). She has no verbal communication but is able to use a few signs and is learning to use an iPad as a communication aid. Linda was diagnosed as being on the autistic spectrum before she started school. She is very short in stature but has no physical disabilities.

Five themes emerged from the Linda data set:

- communication
- things that were difficult to understand/interpret
- education and learning
- transition
- the impact of others.

These themes run throughout the data collected from intensive interaction sessions, discussions with significant people, documentary evidence, follow-up visits to college and the researcher reflective journal.

4.3.1 Communication

Data relating to communication were collected in a variety of settings: at school, at home and college. The data from school and home were collected through interactive sessions. The college data were collected through observation by the researcher and general interaction with Linda and the staff.

During the interactive sessions at school, Linda used a variety of forms of communication, some of her own making, such as facial expression and gesture. At school, Linda was also taught to use an electronic communication aid, pre-programmed by a member of the school staff. In the initial sessions, she used her iPad as she had been taught. It is pre-programmed with specific phrases and there is a facility to use it for specific words to request things should Linda feel

Uses iPad to say 'hello' unprompted. (Observer notes 23.3.2016)

Apart from the initial use of her iPad to say 'hello', Linda showed little inclination to communicate with me, as the note below indicates.

Eventually Linda lifted her head and looked at researcher with long examining stare. Then she turned her head away again. (Video recording 13.4.2016).

Linda displayed a range of communication activities: some behaviours appeared positive and interactive while others demonstrated her desire to shut out the other person.

Looking away and holding her hands over her ears (Observer notes 23.3.2016)
Laughing (Observer notes 16.5.2016)
Making vocal noises (Observer notes 11.7.2016)

Linda was able to communicate that she understood what was being said to her, particularly at the end of a session.

Linda walked out of the room when told it was the end of the session (Observer notes 16.5.2016)

Throughout the intensive interaction sessions, Linda displayed some communication behaviours that were difficult to understand, as discussed in Section 4.3.2 below.
In the examples described below, it is difficult to understand what Linda is communicating; yet it is apparent that she is communicating something, either to another person or to herself.

Holding her hands together then clapping (Observer notes 9.5.2016)
Rubbing hands together and laughing (Observer notes 16.5.2016)
Rolling on the floor and clapping (Observer notes 20.6.2016)

As the sessions progressed, these communications became more intense and a range of communication activities were included, as shown in the note below.

> Linda moves hands along her legs, behind her back and then lies on the floor, rolls onto her tummy and taps the floor faster and faster (Observer notes 20.6.2016)
> Linda throwing rain stick increasingly harder, laughing and seeming excited (Observer notes 4.7.2106)

It would seem at these times that Linda is trying to communicate her emotions or thoughts. Unfortunately, Linda does not have the vocabulary to communicate emotions and is often in a communication relationship where the balance of power is not with her. The consequence of Linda having no form of emotional vocabulary will be discussed further in Chapter Five.

Likewise, Linda communicates when she is interested in something or someone, even if it is simply to tolerate touch, as shown below.

> Linda held her head down on the table, turned away from researcher. When the researcher touched Linda's hand, she was happy to maintain contact, did not withdraw her hand. Stayed in this position for 15minutes ,yet still with head down not looking. (Video recording 13.4.2016).

In the course of the interactive sessions, Linda demonstrated, with increasing confidence, her ability to communicate to request things. Linda was particularly motivated by and enjoyed the keyboard on the iPad. I, as the researcher, introduced the keyboard into the interactive sessions, copying Linda's use of the iPad keyboard.

> Looking at researcher with close intent (Observer notes 4.5.2106).
> Smiling at researcher (Observer notes 9.5.2106)
> Playing the iPad keyboard and smiling (Observer notes 6.6.2016).
> Looking and picking up instruments and then playing with them (Observer notes 11.7.2016)

As I withdrew from activating the keyboard, Linda's communication strategies developed, as noted below.

> Researcher introduced iPad keyboard. Linda played individual keys and researcher copied. When programme ran out, Linda looked at researcher and smiled as indication she wanted another go. Researcher re-started programme (Observer notes (9.5.2016).

In the following session, I did not respond to Linda's gazing and smiling when the keyboard programme stopped. This pattern of communication continued for a few weeks. Eventually, Linda used her communication aid more directly, as noted below.

> Linda eventually used her communication aid to say 'hello'. Sue then responded by activating the keyboard programme. Linda smiled (Observer notes 16.5.2016)

The following week I did not switch the keyboard on at the beginning of the session as usual. Instead, I simply left the iPad open for Linda to do as she pleased. As the following note indicates, Linda eventually used the iPad to request the keyboard.

> Linda used her communication aid to ask for more, meaning the keyboard (Observer notes 6.6.2106)

Linda began tapping the iPad and then looking at me. I did not respond other than to look back at Linda.

> Linda continued tapping the iPad; eventually she tapped the correct icon and the keyboard appeared much to Linda's delight. By chance she had solved the problem and got the keyboard that she wanted. (Observer notes 13.6.2016)

I continued not to provide Linda with the keyboard programme ready to use. Eventually, she used her communication aid to ask for the keyboard, as shown below.

> Linda used her communication aid to say 'I want piano'. When the keyboard programme cut out Linda repeated with her communication aid 'I want piano'. (Observer notes 4.7.2016)

The above notes demonstrate Linda's functional use of her iPad to communicate. This had not happened before and has implications for the potential development of Linda's functional use of her iPad in the future.

Comments made by members of staff provided insight into Linda's communication in the classroom. After the first introductory session, TA 'D' made the following reflective comment.

> 'That was very interesting, I have never seen Linda communicate like that before.' This comment was followed by a discussion about how, in school, the teaching of the mechanics of communication are often focused upon signs and symbols (Researcher reflective journal 21.3.2016)

TA 'Z', at the end of an interactive session, often attempted to interpret or explain Linda's communication to help my understanding, as noted below.

- Linda usually deletes the words that are at the top of her communication aid. It is unusual for her to keep them as she did today. (Researcher reflective journal 6.5.2016)
  Linda was leaning towards you, that is an indication that she knows you are copying her. (Researcher reflective journal 16.5.2016)

TA 'Z' revealed that staff working in the classroom needed to speak to Linda very carefully, taking particular care not to use negatives. This was useful information that I was not aware of and could indicate Linda's attempt to take control of a situation. It is also interesting that, in this situation, she chooses to throw objects, an activity she used when she was feeling in control in the interactive sessions as noted below.

> Unthinkingly, I said 'no' to Linda about something in the classroom. Linda became very upset and began throwing objects. Staff are very wary of saying 'no' to Linda. (Researcher reflective journal 20.6.2016)

After Linda had left school, the interactive sessions were continued at home. On the first occasion, Linda's mother observed. After the session, she made the following comments.

> I have only seen Linda behave in that way with myself and one other person. (Linda's mother)
> I often copy Linda myself in an interactive way like you did.(Linda's mother)
> (Both comments from Researcher notes 23.8.2017).

It was interesting to note that some communication behaviours were the same at school and at home. Some were apparent throughout the period of data collection, such as eye contact, hand movements to cover face and ears and, smiling rocking, while others emerged towards the end of the school sessions. It was interesting to note that these behaviours continued in the domestic setting, as noted below.

> Vocalisation (G 51) intermittent throughout session (Researcher notes 9.9.2106)
> Giggling and laughing (Researcher notes 23.9.2016)

It would be possible to conclude, therefore, that communication behaviours were consistent in the two different settings. It is also interesting to note that new behaviours were carried into a different setting.

Some communication behaviours were only exhibited by Linda in the home. She initiated the sharing of her favourite book of carols, as shown in the note below.

> Linda found the Usborne book of carols. Pressed the music keys and sang along with the carols. She was happy for me to join her in this activity. (Researcher Notes 25.11.2016)

In the home setting, we began to use a specific shared sign when the session was finished and Linda was happy to participate in this.

> At end of session we did high 5. This provided a less abrupt end to the session. (Researcher notes 25.11.2016)

Linda began to initiate activities that I followed. This was probably because she was in a room that she felt was her own, with her own belongings around her.

> Linda introduced activities banging drum, xylophone, tambourine and throwing a soft ball around the room. (Researcher notes 18.11.2016)
> Linda throwing soft ball around the room. Stopped and wanted me to copy her but there was no specific turn taking. (Researcher notes 25.11.2016)

She probably felt much more in control at home than when she was in school. The resources and activities available were less school-focused. Data were collected under different circumstances to school, with greater potential for researcher bias.

At the beginning of the research project, I met with Linda's parents to discuss the plans. They made the following comments about Linda's communication.

> Linda's communication is not at all pro-active at home. Maybe this is because the family are used to interpreting her surroundings for her.
> Linda's mother felt that Linda's autistic traits had an impact upon her communication because Linda liked fixed rigid routines.
> Linda's mother said that sometimes Linda was unexplainably tearful. She thinks this may be because she may be reminded of previous events that have made her feel sad or uncomfortable. (Researcher notes 13.5.2106)

When I made follow-up visits to see Linda in her college placement, it became apparent that Linda was not really encouraged to communicate. At lunchtime, she was given regular verbal and some physical prompts to encourage her to eat, as can be seen from the notes below.

> Linda almost fed. She was given constant prompts, having the food put on the fork for her. Linda did not seem very interested or motivated, very slowly eating. (Researcher notes 7.2.2107).

At the end of the data collection period, I met Linda's parents to give them feedback on the research. Initially, they were particularly interested to hear feedback from my recent visits to the college that Linda is currently attending. I explained that at college Linda received a great deal of support at lunchtime. Her fork was often loaded for her and she usually needed a verbal prompt to encourage her to feed herself. Linda's parents were surprised to hear this, as reported in the notes below.

> We are surprised about this. If Linda is given help then she will assume that is what is expected of her and carry on in that way although she is able to do things herself. (Researchers notes 15.3.2017)

On the first occasion, I had an interactive session in the family home, Linda's mother observed the session and made the following comments.

> I have only seen Linda behave like that with myself and one other person. I often copy what Linda does myself in a similar interactive way.
> (Researcher notes 22.8.2017)

I explained that, in the interactive sessions, I had been able to stand back and wait for Linda to initiate communication and activities. Linda's parents said this was often difficult to achieve, re-iterating my reflection in the box above.

> People love Linda; they want to protect her and do things for her. (Researcher notes 15.3.2017)

Linda's behaviour remained a cause of anxiety for her parents, as they were not confident of how she would behave in any given situation. Anxiety surrounding Linda's behaviour may lead others to act in a way that denies her the opportunity to communicate through her behaviour.

> We manage her behaviour by pre-empting any potentially difficult situations. We think this is what the school staff did. (Researcher notes 15.3.2017)

For young people with communication difficulties, challenging behaviour can be a form of communication. We also discussed Linda's tolerance of noise, as reported below.

> I think Linda indicates she wants to go to the time out room because she wants to get away from noisy people in the group. The 1-1 is available to take her out of the classroom. (Linda's mother. Researcher notes 15.3.2017).

Support strategies used in the classroom were not carried over into lunchtime. At college, the communication aid was left in the classroom over the lunch period.

> I suspected Linda was not using her communication aid. At college only 5-10% of the charge is used. At school 60% was used every day. I know this because I have to charge it when Linda comes home each day. (Linda's mother. Researcher notes 15.3.2107)

Both Linda's parents spoke a great deal about Linda's tearfulness: they were aware that she was expressing something but were unable to understand what she was feeling.

Documentary evidence revealed progress and aspirations regarding Linda's communication skills and development while she was at school. In the review of her Statement in Year 10, the family and education professionals identified what was working well, as noted below.

> Swimming club, communication, behaving well in social situations

The comment below was recorded about Linda by professionals in the meeting and was recorded in the third person, as shown below.

> Using her voice more, using her iPad, being more proactive interested in things

The following comment, however, was written in the first person as though Linda had said it, although Linda would not have been able to express this content. There was no acknowledgement that this comment was actually made on Linda's behalf.

> Develop my skills and interests. Develop expressive arts skills and communication skills.
> What I want to achieve. See my peer group out of school. Stay fit and healthy.

Within the form, there was an opportunity to request additional advice or assessment from another agency. Additional speech and language support was identified, presumably by those attending the meeting, on Linda's behalf.

> Develop communication skills further. Speech and Language Therapist. Ongoing.

The form turns to address the issue of funding, asking if a personal budget is required. In the Year 11 Transfer from Statement to EHCP form, the tick boxes of needs were completed identifying the following needs.

Communication and interaction, cognition and learning and physical.

The transfer document required objectives from the Statement to be converted into outcomes for the EHCP. The following outcomes were recorded for Linda.

Linda to make a choice about her lunch each day reinforcing the vocabulary before, at and after lunch. This will be done daily by class staff.
Linda to have regular activity choices throughout the day at home and school at different times and in different places to prevent habitual choosing. This will be done daily at school/college and home.

Information regarding the extent and impact of Linda's SEN and disabilities were of particular relevance, as this was Linda's final year in school before going to college. It was very important, therefore, to record the level of assistance that Linda required to facilitate her communication development, as recorded below.

Additional SALT time
Training for staff in programming and using iPad.
Staff time to make resources and programme iPad.

Linda will need ongoing support with communication including updating her iPad.

The findings demonstrate that Linda has considerable difficulty with communication and this has a significant impact on her life and the lives of those around her.

4.3.2 Things That Were Difficult to Interpret

Throughout the data collection period, in a range of different circumstances, it became evident that Linda exhibited communicative behaviour that was difficult to understand.

The following incidents were noted in the interactive sessions, possibly in an attempt to communicate with others or possibly as a means of communicating with herself.

Linda hitting the keyboard harder and harder and rocking (9.5.2016)
Linda rubbing her hands together and sucking her thumb while playing keyboard (16.5.2016)

When the keyboard went off, Linda moves her hands along her legs, puts her hands behind her back, lies on the floor, laughs and smiles. Rolls on to her tummy, taps her hands on the floor. Tapping faster and faster. Sits up crosses legs and looks at researcher. Puts her hands up to her face then over her ears. Rolls on to her tummy and starts to tap the floor with her hand. (Observer notes 20.6.2016)

It is interesting to note the increased intensity of the tapping activity, which appears to develop. Linda then shows a range of behaviours, some of which she is happy to share and somewhere she seems to be almost unaware of my presence, as indicated in the notes below.

> Linda takes her turn with the rain stick and throws it. Linda starts to throw it harder and harder. Linda begins to laugh and seems excited, she can't stop laughing. Linda lies back with her hands behind her head. She then picks up the instrument and throws it against the chest of drawers. (Observer notes 4.7.2016)

TA 'Z' revealed that staff working in the classroom needed to speak to Linda very carefully, taking particular care not to use negatives. The throwing behaviour noted below is similar to that noted in the interactive sessions. It is possible that behaviour interpreted as challenging may simply be a means of communication for a person with significant communication difficulties.

> Unthinkingly I said 'no' to Linda about something in the classroom. Linda became very upset and began throwing objects. Staff are very wary of saying 'no' to Linda. (Researcher reflective journal 20.6.2016)

When I first met Linda's parents, they expressed difficulties in understanding Linda, as seen in the comments below.

> Linda's mother said that sometimes Linda was unexplainably tearful. She thinks this may be because she may be reminded of previous events that have made her feel sad or uncomfortable. (Researcher notes 13.5.2016)

Throughout the documentary evidence, it is clear that Linda needs to develop her communication skills and strategies. This is a recognition of the difficulty that people have in understanding Linda.

4.3.3 Education and Learning

Data relating to education and learning were collected from documentary evidence, intensive interaction notes, discussions with significant people and the researcher's

journalistic reflections. They encompass the educational provision experienced by Linda and the learning that is demonstrated in those settings.

The documentary evidence sets out the educational provision for Linda, such as the subjects she studied, as shown below.

> Subjects studied throughout years 9,10 and 11
> Maths, P.E. Life Skills (G26), Swimming and there was a report from the pastoral teacher on each annual report

The documentation also recorded the support that Linda needs to access educational opportunities and draws attention to the need for multi-professional support for Linda.

> Additional SALT time
> Training for staff in programming and using iPad.
> Staff time to make resources and programme iPad.

Targets and outcomes that Linda should achieve were listed, as highlighted below.

> Linda to make a choice about her lunch each day reinforcing the vocabulary before, at and after lunch. This will be done daily by class staff.
> Linda to have regular activity choices throughout the day at home and school at different times and in different places to prevent habitual choosing. This will be done daily at school/college and home.

School played a significant role in Linda's education. Her home circumstances also had an influence on her education, possibly in a less obvious or obtrusive way. When Linda was at school, home and school were in unison in supporting her learning, as indicated in her mother's comment regarding behaviour management below.

> We manage Linda's behaviour at home by pre-empting and trying to understand her. This is also true of the staff that work with Linda and know her well. (Researcher notes 15.3.2017).

This was not the case when Linda started at college: on one occasion she was sent home from college because she had been throwing things and was tearful. Linda's mother kept her at home all week, although on Tuesday she seemed fine and quite settled. Linda's mother disclosed that she was anxious about sending Linda back to college in case she misbehaved.

> I was wary about sending Linda back to college on Tuesday in case she misbehaved again. I kept her off for the rest of the week. (Researcher notes 2.12.2016)

While Linda was at school, her learning and achievement were noted in annual review reports, in which the reporting of achievements was personalised with considerable detail including personal comments. Teachers responsible for individual subjects wrote the comments noted below.

> Year 9 Maths: Linda can sort cutlery with help.
> Year 9 English: Linda can follow the sequence of pictures when she is listening to a story.
> Year 10 IT: Linda uses her iPad to ask to go on the computer.
> Year 11 Community Skills: Linda can use the self-service check-out with help.

Other instances of Linda demonstrating learning were evident but not specifically recorded in the documentary evidence. The teaching assistants told me that Linda had learned to use the toilet. The comments of the teaching assistants are noted in the box below and make particular reference to Linda's transfer to college.

> We have spent the last 2 years toilet training Linda. TA 'A'
> We have a detailed toilet programme. I hope the college will follow it. TA 'D' (Researcher reflective journal 13.7.2016)

During my visit to the college, I observed Linda moving to and from the dining hall confidently. She had learned this in the two months since she had started there.

> Linda found her way from the classroom to the dining hall with the rest of her class. She stood appropriately in the queue waiting to go into the dining hall. (Researcher notes 7.2.2017).

Following my visit to the college, I spoke with Linda's parents and explained that at college Linda received a great deal of support at lunchtime. Her fork was often loaded for her and she usually needed a verbal prompt to encourage her. At home and school, Linda fed herself independently with the occasional verbal prompt. They replied as noted below.

> We are surprised about this. If Linda is given help then she will assume that is what is expected of her and carry on in that way although she is able to do things herself. (Researcher's notes 15.3.2017)

Linda learned how to behave in certain situations, but this did not necessarily increase her independence or autonomy as a person. The above example illustrates that Linda was unable to transfer the independence skills she learned at home into a new setting and demonstrates the importance that people supporting Linda are fully aware of her

prior learning, particularly at times of transition. There are many aspects to Linda's education and learning at school: she follows some mainstream subjects such as Maths and PE but also additional subjects such as Life Skills, which covers developing personal care skills and managing lunchtime routines. Communication played a significant role, from developing the range of communication to being encouraged to make choices. It was important to note the amount and focus of the support Linda received alongside her educational progress. The very personalised approach to Linda's education and learning, while she was at school, was not as evident when she transferred to college.

4.3.4 Transition

At the time of the data collection, Linda was in Year 11, her final year at school, and the data were collected at school and her post-school college placement. The data comprise transition planning documentation, notes from visits, discussions with significant people and researcher reflections.

The transition plan for Year 9 takes the form of an action plan written from Linda's point of view, although there was no evidence within the document that she had contributed to the discussion, as mentioned in Section 4.3.1 above. Throughout the document, a considerable emphasis was placed on asking Linda what her support needs were, as seen in the extract below.

> Do you want to stay in education? Yes
> If so what course would you like to do? Linda will take part in the College link programme (G7) in Year 11 to help her to make choices about which post-16 placement and course she would like.

The question is posed to Linda and the response is made by another person on her behalf. Lit

The document is based on a fundamental contradiction: it is addressed to Linda and asks her complex questions about her future and her support needs but, from the responses that are given on Linda's behalf, it is apparent that Linda is not able to respond to the questions. She would need to make considerable progress to be able to make a more reasoned response on her own behalf. The form thus records other

people's interpretation of Linda's wishes; there is no evidence of her wishes regarding the transition process, as shown in the extract below.

> How could you be supported to join in the community?
> Linda takes part in holiday clubs in the community. This requires a high level of support from people who know Linda and understand her well.

The form is typed predominantly in a small font and uses only four symbols/pictures in the entire form. Although it is completed as if Linda had contributed to the discussion, she would have not understood its contents; it is not accessible to her. The following comments are written as though Linda had expressed them although she would have been unable to express such complex ideas.

> Developing my skills and interest
> My friendships and relationships
> Feeling healthy and good about myself
> Where and how I want to live in the future (independent life skills)

The transition plan in Year 10 is a part of the annual review of Linda's statement of SEN. It is a formal document recording the review meeting. It is striking when reading the form that certain sections are complete and others left completely blank, as seen in the extract below. It appears that those in the meeting assumed that any form of voluntary work was not an option for Linda.

> Do you want to stay in education? Yes
> Would you like to do some voluntary work? If so, what would you like to do? [This question was left completely blank, no response at all].

The plan includes questions relating to future aspirations. It was interesting to note the discrepancy between how the question was asked and how the answer was recorded, as the extract below demonstrates.

> What are your hopes, dreams and ambitions for the future?
> To continue with the things she enjoys like music, Expressive Arts and to be with friends.

The question was addressed to Linda. The response was assertively given by another person on her behalf. This highlights a confusing situation for all stakeholders. Throughout the document, a considerable emphasis was placed on asking Linda what her support needs were, as seen in the extract below.

> Do you want to stay in education? Yes
> If so what course would you like to do? Linda will take part in the College link programme (G7) in Year 11 to help her to make choices about which post 16 placement and course she would like.

The Year 11 Transition document is very sharply focused; there is no hint of the 'blue sky thinking' apparent in the Year 10 Transition document. All the questions are sharply focused on education, voluntary employment or training. Assumptions about independent living (G23) are implicit. The questions are asked of Linda but someone else is giving their interpretation of Linda's link visits to college, as noted below.

Do you want to stay in education?
Yes, Linda really enjoyed her transition link at college. She responded well to all the activities and to the environment.

The question below is not answered.

What training options or apprenticeships are you interested in? What have you looked at? What further help do you need?

This probably indicates that, at that stage, training was not deemed appropriate for Linda. Throughout the Year 11 Transition document, there is frequent reference to the amount of support that Linda thinks she will need. This refers to the education setting, living accommodation and community.

How could you be helped to prepare for independent living?
Think about where you would like to live and who with.

How could you be helped to join in where you live? Do you need help with getting about and transport? Do you have friends or know people who can help you?
Linda will need support to be able to join in any activities. She will need help getting about and will need to be accompanied on any form of transport.

There remains an underlying contradiction in asking Linda questions that she cannot answer, particularly given the very limited support and preparation that she received before each meeting. In this respect, the recording documentation for the Transition meeting was tokenistic, asking the subject of the form direct questions in an empowering manner but denying that person the means to participate in the meeting in a manner that is meaningful to them.

Other aspects of Linda's transition were revealed through discussion with significant people and observations. For Linda, a crucial element of her transition to college was

the management and continuity of aspects of her care. The school staff had expended considerable thought and energy to enable Linda to use the toilet independently, as noted in a comment from a TA below.

> We have spent the last 2 years toilet training Linda. TA 'A'
> We have a detailed toilet programme. I hope the college will follow it. TA 'D' (Researcher reflective journal 13.7.2016)

When I observed Linda at college, I saw Linda being taken to the toilet, as noted below.

> Linda got up willingly when asked and followed the member of staff to the toilet. A member of staff accompanied Linda throughout going to the toilet. (Researcher notes 21.2.2017)

I observed at college that Linda had 1-1 support at lunchtime and was given regular verbal and some physical prompts to encourage her to eat her lunch.

> Linda almost fed. She was given constant prompts, having the food put on the fork for her. Linda did not seem very interested or motivated, very slowly eating. (Researcher notes 7.2.2017).

I made the following comment in my journal.

> Lunchtime is not seen as important as it is not part of the student's learning. (Researcher notes 21.2.2017).

There did not seem to be any teacher or classroom assistant input at lunchtime. The following comment was recorded in the research journal.

> No apparent teacher or teacher assistant in dining hall. Need to follow this up. (Researcher notes 7.2.2017)

On my second visit to the college, I asked the head of department about the deployment of staff at lunchtime. She referred me to a teaching assistant who was responsible for the organisation of lunchtime staff as I recorded in the notes below.

> When I spoke to the lead mentor responsible for the organization of lunchtime staff he said it was his job simply to organize the staff; he had no responsibility for how the lunchtime staff did their jobs.(Researcher notes 21.2.2017)

Linda seemed confident moving to and from the dining hall.

> Linda found her way from the classroom to the dining hall with the rest of her class. She stood appropriately in the queue waiting to go into the dining hall. (Researcher notes 7.2.2017)

Linda was able to find her way back from the dining hall to a room where the students spent their free time after lunch and seemed relaxed in this situation, as noted below,

> Linda spent her free time sitting on a cushion dangling a toy. She did not interact with anyone but was happy to interact with me when I approached her. (Researcher notes 7.2.2017)

I spoke to the college lunchtime supervisor who explained the following.

> There are four lunchtime staff for this large group but when they are in the classroom they have one teacher and three teaching assistants for each class. (Researcher notes 21.2.2017)

The implication seemed to be that there were insufficient staff at lunchtime.

The follow-up visits highlighted varying expectations in the different situations that Linda experienced. At school, she was encouraged to be more independent and emphasis was placed on the use of her communication aid in realistic situations. This was not so evident at college. Linda had to assimilate the different expectations made of her which she seemed to do passively, despite demonstrating a considerable level of independence when walking around the college. Linda's parents were surprised to hear that Linda was not feeding herself at college and made the following comment.

> Linda never had 1-1 support at school. It is not always helpful. Linda is probably the most vulnerable young person in the group and it is a way of keeping her safe.
> (Linda's Mother. Researcher notes 15.3.2017)

I explained that there was very little communication between the teaching staff and the midday staff. Support strategies used in the teaching situation were not carried over into lunchtime. This was very different to the experience that Linda was used to at school, as was evident in the use of her communication aid. At school, she took it everywhere with her and was able to use it to select her lunch. At college, the aid was left in the classroom over the lunch period. Linda's mother made the following comment.

> I suspected Linda was not using her communication aid. At college only 5-10% of the charge is used. At school 60% was used every day. I know this because I have to charge it when Linda comes home each day. (Linda's mother. Researcher notes 15.3.2017)

It was agreed that there had been no major disruption over Linda's introduction to college. Her parents and I discussed the use of 1-1 support for her at college and also discussed her tolerance of noise. Her parents made the following comments.

> I think Linda indicates she wants to go to the time out room because she wants to get away from noisy people in the group. The 1-1 is available to take her out of the classroom. (Linda's mother. Researcher notes 15.3.2017)

Overall. Linda's parents felt that she had coped well with the transition from school to college, although it was not always straightforward. The fact that she was walking around the college with confidence was an achievement in itself.

Both Linda's parents spoke a great deal about Linda's tearfulness and its possible meaning. It obviously caused them concern, yet they did not know what to do about it. They also spoke of the way Linda's behaviour had been addressed at school and how they did the same at home. The situation with college was different.

> We manage Linda's behaviour at home by pre-empting and trying to understand her. This is also true of the staff that work with Linda and know her well. (Researcher notes 15.3.2017)

Linda's parents asked me to go back to the college to give feedback on what I had observed. They did not feel confident to challenge the issues themselves despite their concern. Throughout Linda's first term at college, I had weekly interactive sessions with her in the family home which enabled me to have incidental dialogue with Linda's mother. At the end of Linda's first week at college, her mother commented.

> The week has gone well. Linda has come home relaxed. The transport is OK. This is a huge relief. (Researcher notes 9.9.2016)

Later in the term, I witnessed Linda's mother's frustration with the system. She felt she was providing the various authorities with information but was not being listened to, and information was not being correctly recorded, as the comment below indicates.

> They had attended a meeting at the school a year previously to trigger the creation of transfer from a statement to an EHCP. Now, a year later, they received the documentation ready for a review meeting at the college that was due in a couple of weeks. There was no time to correct the inaccuracies. This made the parents feel very vulnerable going into the meeting with college staff who they did not know very well. (Researcher notes 25.11.2016).

In December, when I arrived for an interactive session, Linda's mother was upset, as recorded in my notes below.

> Linda was sent home from college on Monday because she had been throwing things. Linda also seemed sad and was crying. (Researcher notes 2.12.2016)

Linda's mother had kept Linda at home all week, although the following day Linda seemed calm and relatively settled. Linda's mother disclosed that she was anxious about sending Linda back to college in case she misbehaved again, as noted below.

> I was wary about sending Linda back to college on Tuesday in case she misbehaved again. I kept her off for the rest of the week. (Researcher notes 2.12.2016)

The above comment and sequence of events demonstrate a lack of trust between Linda's parents and the college at the end of Linda's first term there. In my reflective journal, I recorded the following comments.

> Thoughts about second visit to college. Felt more relaxed today. Everything felt more familiar. An interesting balance of familiarity but must remember to remain objective. This could cause possible confusion/ conflict in the research process? (Researcher reflective journal 21.2.2017).

> Despite feeling confused and challenged by the college situation, I must remain objective yet acknowledging my confusion and conflict to myself within the research process. (Reflective journal 21.2.2017)

I had to shift my thinking with honesty and openness to accommodate the data I had collected at the college. The college worked on a different system to the school: the school was a specialist provision, whereas the college was an inclusive provision, providing for degree-level students as well as those with similar needs to Linda.

4.3.5 The Impact of Others

Linda is dependent on the support and understanding of other people because of the severity of her difficulties. This means that other people have a very significant impact on her life and opportunities.

This research project focuses on the transition process for young people with PMLD when they leave school in Year 11. It is clearly stated in government legislation that all

young people should have the opportunity to influence their own transition planning. Although Linda attended the meeting, she was never allowed to express herself or influence the meeting. Other people repeatedly spoke on her behalf, even though the questions in the documentation were addressed to her. The people who designed the documentation and those who managed the meeting had a significant impact on Linda's ability to contribute.

In all the reports, Linda's achievements were reported with a high degree of personalisation, with considerable detail provided by subject teachers.

> Year 9 Maths: Linda can sort cutlery with help.
> Year 9 English: Linda can follow the sequence of pictures when she is listening to a story.
> Year 10 IT: Linda uses her iPad to ask to go on the computer.
> Year 11 Community Skills: Linda can use the self-service check-out with help.

It is not clear who expressed Linda's point of view below, but it must be assumed that it was a member of the school staff as it is noted that her parents do not comment.

> From Linda's point of view, it was noted that she does not like it if she can't go outside for break if it is raining.
> The school noted that Linda's interaction with her peers needed to improve and the management of her behaviour when affected by her menstrual cycle.
> There was no comment from Linda's parents.

The school makes further comments.

> School point of view, increased communication, increased curiosity, progress in mark making. [The family section was left blank.]

Clear EHCP outcomes, as noted below, were identified for Linda by teachers and other professionals, with no input from Linda herself.

> Statement objective: To develop an understanding of basic concepts so that she can access an appropriate curriculum.
> EHCP outcome : To make clear and informed choices throughout her day, having the opportunity to use her iPad at all times.

The above statements have a significant impact on Linda, as does the fact that she was not able to make any contribution to any part of the reporting or decision-making.

The comment below illustrates how teaching assistants are often keen and willing to think more deeply about young people with PMLD. It is not clear from the comment

whether teaching assistants are given the opportunity to develop these thoughts within their role. This will have an impact on Linda and the way in which teaching assistants respond to her.

> 'That was very interesting, I have never seen Linda communicate like that before' This comment was followed by a discussion about how, in school, the teaching of the mechanics of communication are often focused on signs and symbols (Researcher reflective journal 21.3.2016)

Young people with PMLD have very complex difficulties and it can be very difficult to understand and communicate with them, as noted by Teacher 'E' below. This feeling of insecurity will potentially have an impact on the confidence that staff feel when interacting with Linda.

> PMLD students really challenge me. They make me feel very de-skilled. (Reflective journal 13.4.2016)

My discussions with Linda's parents revealed that people wanted to protect Linda and to do things for her. Her parents said that at home as at school, they tried to pre-empt any difficult situations that might cause Linda distress or result in Linda displaying challenging behaviour. These attitudes towards Linda will influence the way she perceives herself and her relationship with other people. In December, when I arrived for an interactive session, Linda's mother was upset because Linda had been sent home from college because she was throwing things, as mentioned in the previous section 4.3.4. In this instance, the college staff did not appear to try to understand the meaning of Linda's behaviour, and the subsequent lack of confidence displayed by Linda's mother had a significant impact on Linda.

I made notes following each interactive session I had with Linda in her home, as can be seen below.

> Excellent session (Researcher Notes 22.8.2016).
> Linda very communicative (Researcher Notes 9.9.2016)
> Excellent session (Researcher Notes 18.11.2016)

These comments reveal the underlying attitudes of the researcher toward Linda. In effect, they are value judgements upon the sessions and highlight that so much of Linda's life is affected by the value judgements of others to which she does no

opportunity to respond with her point of view. In my reflective journal, I recorded the notes below.

> I am not sure Linda knows what is expected of her in the interactive sessions. (Researcher Reflective Journal 4.5.2016)

Within the freedom of the interactive sessions, at first, Linda seemed bewildered as she is directed by others for much of her life. Her communication aid is programmed and its use directed by others. Linda's behaviour is interpreted by others and any difficult behaviour is circumvented. When Linda moved to college, she quickly adopted a passive role, as demonstrated at lunchtime. These underlying attitudes, although well-intentioned, have a significant impact on Linda's ability and confidence to use whatever communication strategies she has to express her wishes and emotions.

4.3.6 Concluding Comments – Linda Case Study

Linda was seemingly a compliant young person at school although her parents did express concerns regarding some behavioural issues at home. At school and home Linda exhibited outbursts of emotional behaviour. It would seem that she had no means of expressing emotions and frustrations; this lack was managed by other people pre-empting the situations that might upset her. Much of Linda's life was managed by others, including the way her communication aid was programmed. This had the potential to create passive responses from Linda, as demonstrated in the lunch hall at college, when she was happy to be fed despite not being fed either at home or at school. This underlying learned passivity can become a hindrance to personal autonomy and advocacy. The young person runs the risk of becoming more dependent rather than less as they move into adulthood. This will be discussed further in Chapter Five.

4.4 Katy

Katy was in Year 9 at the time of the data collection. She cerebral palsy (G4) and is hemiplegic (G20); she has full use of one arm and hand but the other has limited movement. Katy cannot communicate verbally and is dependent upon others interpreting a variety of communication strategies that she has developed herself. This is a very vicarious means of communication for Katy.

Six themes emerged from the data collected for Katy:

- Communication
- Education and Learning
- Transition Planning
- Health
- Impact of Others
- Thoughtfulness.

These themes occurred throughout the data sets from Intensive Interaction, discussions with significant people in Katy's life, documentary evidence and researcher's reflections. The emphasis of the different themes in the data was variable.

4.4.1 Communication

Katy has significant difficulties including mobility difficulties, epilepsy and fine motor coordination problems and she is unable to make any meaningful utterances. These conditions make it impossible for Katy to use any form of mainstream communication. She cannot use reliable utterances to communicate and her motor difficulties inhibit her capacity to use any form of communication aid. Katy has developed her own communication system which includes a range of indiscriminate utterances and sounds, a few gestures and facial expressions. Katy also displays a look of interest and listening which is probably an attempt to pick up on cues from other people around her. This communication activity developed throughout the 1-1 sessions. In the first session, Katy initiated very little communication but responded to touch, as noted below.

> Katy listened when Sue made a sound. She moved her eyes from side to side. (Observer notes 14.3.2016)

During the final sessions, Katy was initiating and maintaining strings of communicative activity using a range of the skills that were familiar to her. She now had the confidence to use her own communication system and it was working for her in the receptive environment of the interactive sessions, as shown below.

> Katy was shaking and throwing the bells and giggling as she was doing this. She was thrusting her hand forward several times to initiate an interactive exchange. Blowing raspberries, making kissing sounds. (Notes of video recording 10.11.2016)

Throughout the 1-1 sessions Katy demonstrated a wide range of communicative activity, including touch, sounds, gestures and facial expression.

There are a variety of forms of touch. As the sessions developed, Katy's desire to touch and sustain touch became more evident. The examples below demonstrate Katy's willingness to tolerate the touch of another person and her own desire to reach out to touch others. She develops this to include clapping with another person, enabling two people to share at her own initiation.

Katy reach out to touch Sue's hand and pulled it close to her body. (Observer notes 20.6.2016)
Katy clap her hand on to Sue's hand. (Video notes 7.10.2016)

Katy demonstrated her use of touch to indicate levels of engagement with and sustained interest in particular objects, as demonstrated below.

Throughout the session, Katy was touching and twiddling the Velcro of the splint (G45) on her right hand. (Observer notes 13.4.2016)
Katy reaching out touching the bells and other instruments, shaking them. (Observer notes 27.6.2016)

Katy uses touch to demonstrate when she does not want something, by pushing it away, as shown in the notes below.

Katy touched the iPad and pushed it away. (Observer notes 13.4.2016)

At the beginning of the 1-1 sessions, Katy made very little sound. She lay almost motionless, as the notes below indicate.

The only intentional sound that Katy made was a swallowing sound that Sue copied. She made this sound a few times. (Observer notes 14.3.2016)

In the following session, Katy ventured to make a sound that she frequently used in the classroom. This was repeated in subsequent sessions.

Katy made her la, la, sound. (Observer notes 17.3.2016)
Katy made la, la sound. (Observer notes 9.5.2016)
Katy making la, la sound and b, b, b. (Video notes 10.11.2016)

Katy continued to extend the repertoire of sounds that she used in the sessions, as shown in the examples below.

Katy was sighing intermittently in the session. (Observer notes 23.5.2016)
Katy deep breathing. It was noted that at the end of the session Katy was smiling and laughing. (Observer notes 20.6.2016)

Sounds of enjoyment became a regular feature of the sessions.

Katy giggling. (Observer notes 13.6.2016)
Katy laughing towards the end of the session. (Observer notes 20.6.2016)
Katy laughing. (Video notes 10.10.2016)

On a few occasions, Katy made sounds that were more difficult to attribute a particular meaning to, as shown below.

Katy made vocal noises and kissing sound with her lips. (Observer notes 16.5.2016)
Katy making a clicking sound and moving her jaw backwards and forwards. (Observer notes 6.6.2016)
Katy sighing. (Observer notes 23.5.0 2016)
Katy making deep breathing sounds. (Observer notes 20.6.2016)
Katy blowing raspberries. (Video notes 7.10.2016 and 10.10.2016)

It was tempting to put an interpretation on the sounds, thinking that Katy was bored or dissatisfied. The sounds could, however, indicate that she was thinking, reflecting.

In the first three 1-1 sessions Katy made no gestures. The introduction of a variety of objects seemed to have an animating effect upon her and she began to use a variety of gestures, as shown below.

Waving her arm/hand. (Observer notes 4.7.2016, 11.7.2016, Video notes 10.11.2016)
Clapping (Observer notes 13.6.2016) hands together on her chest (Observer notes 11.7.2016)
Putting her hand up and out (Video notes 4.5.2016) This developed into a hand/arm thrust (Video notes 1.11.2016)

The continued use of objects in the sessions prompted further use of gestures by Katy.

Katy was waving her hand. Clapping her left hand on to her right hand. Throwing things away. (Observer notes 4.5.2016)
Katy throwing things away. (Observer notes 9.5.2016)
Katy waving her arm. (Observer notes 16.5.2016)

There were a few other occasions when Katy used gestures that were difficult to interpret. Sometimes it appeared that she was taking time to think, as can be seen in the notes below.

Katy started to rub her eyes when the session was about to end. (Observer notes 6.6.2016, 13.6.2016).
Katy held her head down. (Observer notes 20.6.2016)

It was possible to think that Katy was rubbing her nose because she was thinking about the end of the session, particularly as this happened on two consecutive sessions. Holding her head down would seem more explicitly to indicate that she was taking time out from the session for some reason. Katy demonstrated no facial expression that was worthy of recording by the observer during the first few sessions. Gradually, Katy's facial expressions began to emerge, often indicating a sense of caution, as can be seen below.

Katy frowning. (Observer notes 13.4.2016)
Katy grimacing. (Observer notes 4.5.2016)

They gradually developed into more sustained relaxed expressions.

Smiling (Observer notes 4.5.2016, 16.5.2016) (Video notes 10.10.2016, 1.11.2016)
Sticking her tongue out (Observer notes 6.6.2016)

Katy occasionally used other facial expressions. It was difficult to attach any particular meaning to them but important to note them as they demonstrate the range of expressions that Katy was able to use.

Moving her eyes around and blinking. (Observer notes 6.6.2016)
Yawning (Video notes 10.10.2016)

Most of Katy's communication system was aimed at communicating with other people. She spends very little time and energy in solitary communication with herself. Katy's communication system appears to be effective for her in that she does not appear to be frustrated or withdrawn. As the data demonstrates, it was not a precise form of communication and was open to interpretation.

The data for the interactive 1-1 sessions shows throughout evidence of Katy taking time to listen and reflect, to think things through. In the notes below, the observer made a judgement that Katy was listening for the beads but no explanation is given as to how the observer knows that Katy was listening particularly for the beads.

Katy was listening for the beads. (Observer notes 6.6.2016)

There was subsequent additional information to substantiate evidence of listening. This was usually in the form of accompanying behaviour to reinforce the listening behaviour.

Katy listen when Sue makes a noise, she moves her eyes from side to side. (Observer notes 14.3.2016)
Katy lifts her head and is listening towards the end of the session. (Observer notes 16.5.2016)

Thoughtfulness followed by action indicated times when Katy was listening and being attentive to specific things around her. The periods of thoughtfulness were usually followed by a specific action, as demonstrated below.

Katy listen to rain stick, hands on chest. Still make no sound. (Observer notes 11.7.16)
Quiet reflection. Katy can't reach beanbag. Stop to think. Eventually reach beanbag. (Video 7.10.16)
Katy stop interaction, sit quietly then start blow raspberry. (Video 1.11.16)

From these observations, it was clear that Katy was taking time to think things through to solve problems, for example, finding and holding the instrument. She took control of the situation when she stopped engaging with the current activity and introduced a new one, raspberry blowing. She was also using this quiet reflective time to make decisions, for example, to decide which way to throw the beanbag as part of the interactive game that she had initiated. The data suggests that listening was important for Katy. Everyone has the facility to listen to external things but equally important is the facility to listen to our internal conversations, the thoughts that we have with ourselves. The example below demonstrates Katy's willingness to respond to interactions initiated by another person.

Katy kept her hand on Sue's hand when Sue touched Katy's hand. (Observer notes 14.3.2016 and 17.3.2016)

There are times when a young person may make a seemingly random action with no particular meaning. If the interactive partner responds to the activity, endorsing it and giving it meaning, this can develop into a meaningful interactive activity. From the example below, it was possible to see that the response to the throwing and the validation of the activity reinforced Katy's desire to throw the necklace again, anticipating a similar response. Hence, an interactive game emerged, in which Katy was in control because of the sensitive response of her interactive partner.

Katy threw the necklace onto the floor. Sue picked them up and gave them back to Katy. Katy threw the necklace again and Sue again returned them. A throwing game began. (Observer notes 16.5.2016)

As the interactive relationship developed, so did Katy's confidence, so that she began to reach out to the other person. It is a vital part of any interaction that each person has sufficient confidence to reach out to the other.

Katy reached out to touch Sue's hand. (Observer notes 11.7.2016)
Katy reached out to touch Sue. (Video notes 10.10.2016)

Interactive communication is essentially about sharing and, in order to share, each person must be open and inviting towards the other. Katy began to reach out to the other person. Gradually interactive games began to develop with Katy; once established, the game pattern revealed depths of Katy's thinking and interactive communication. In the examples below, the enjoyment, fun and sharing of the participants are evident.

Katy throws the beads intentionally in different directions for Sue to retrieve. (Observer notes 27.6.2016)
Katy throws the beads sometimes intentionally to Sue and sometimes not. Teasing. (Video notes 7.10.2016)
Katy taking the beads from Sue's hand. (Video notes 10.10.2016)
Katy laughing and intentionally throws the beanbag away from Sue. (Video notes 1.11.2016)

By a process of modelling, Katy learned from her interactive partner the essential aspects of interactive communication and how to make the experience meaningful and fun for herself. The process developed from tolerating a fairly passive interaction from the other person to initiating interactive communication and, eventually, led to playful teasing interaction. Only when we know and trust someone do we have the confidence to tease them! This demonstrates that Katy has a range of interactive communication techniques and a willingness to use these in participation with another person.

The data have shown that Katy has her particular communication system that she is capable of using to develop meaningful relationships with another person. She is dependent on how the other person responds to her and needs confidence and modelling of behaviours to encourage her to reveal herself. When these attributes were apparent in the 1-1 session, Katy demonstrated that she essentially has an extrovert personality and enjoys engaging with other people. Katy enjoyed sharing her personality in a mutually equal relationship.

Although Katy has shown herself to be an extrovert, she also needs time for quiet reflection and time to process. When given this time, she is able to develop the quality and purpose of her communicative interactions, thereby giving them more meaning for all involved. When Katy was out of her wheelchair, lying comfortably on a large beanbag, she was more relaxed and responsive than when in her wheelchair, when her reactions were much more restricted.

In the classroom, I observed Katy being given a tray of shells. She was then left with the shells. She systematically threw the shells away from her all over the floor. When the tray was empty, a member of staff would quickly pick up the shells, return them to the tray and the process would continue. The activity was very solitary for Katy. In the interactive sessions, the interactive partner responded promptly to the throwing activity and this, consequently, became the foundation of a meaningful and entertaining communicative activity for the two people to enjoy. This is an example of how opportunities for communicative interaction are missed, simply because those around the young person are not looking for the potential meaning that the activity may have for the young person.

The documentary data provided further insights into communication in Katy's life. The Annual Review report contained a detailed explanation of particular achievements Katy had made during the year. The comment below demonstrates aspects of Katy's communication – anticipating and responding to the actions of another person.

> Katy will reach out for an item she knows someone is going to pass to her.

Each teacher is given the space to include a comment on Katy during the year and some teachers use it to comment on the quality of Katy's involvement with various curriculum activities, as seen below.

> Katy enjoys the social aspects and is becoming more in tune with emotions of those around her, for example joining in with laughter at something funny.

Achievements in communication were noted, including the important aspect of making choices.

> Katy has begun to engage with her DELL communication aid. (G13)

> It is wonderful to see the progress that Katy is making. She is making choices and is actively engaged with her learning.

Specific future targets for Katy's communication are also identified within the Annual Review.

> To follow individual communication targets.
> To develop the use of her DELL communication aid (G13)
> Katy to use her DELL communication aid to make simple choices.

Speech and Language Therapy is noted in a list of the current provision that Katy receives.

> Small group teaching. Weekly Physiotherapy, An IEP. Support from Speech and Language Therapy and Occupational Therapy.

The objective from Katy's Statement of Special Educational Needs was converted into an outcome as shown below.

> Objective: To be able to communicate with others and understand language so that she can make her needs known and follow simple instructions.
> Outcome: To make regular clear informed choices throughout her day using her Dell communication and vocal response choices.

I record moments of doubt, feelings specifically linked to Katy not responding; not responding is a form of communication. I think about this in greater depth. This form of communication can harm the person who is trying to communicate. My journal entry records my feelings of rejection and subsequent elation.

> Within the sessions I sometimes have a sense of rejection when Katy does not respond. In the sessions I deal with the rejection but I feel elated when a connection is made with Katy. (Journal 22.6.2016)

When Katy did not wish to communicate, I sought an explanation; yet it is a common human phenomenon not always to feel communicative when you are with another person. My record below endorses this.

> Katy was not interacting with her usual enthusiasm today. Why? Was she bored? Was it because we had a different TA as research assistant? (Journal 23.5.2016)

I comment on those things that happened in the session that I think are particularly worthy of note. The note below is specific to communication and the impact of Katy's physical position on her communication.

> Good sitting today. Katy doing increased vocalization. Intentionally reaching out to touch me. Katy also seemed thoughtful at times. (Journal 6.6.2016)

The data demonstrate that Katy has a range of communication strategies but their effectiveness is dependent on the sensitive response of people around her.

4.4.2 Education and Learning

There are times when a young person with PMLD may make a seemingly random action with no particular meaning. If the activity is responded to and endorsed, it is given

meaning. From the example below, it is possible to see how the response to Katy's throwing and, thus, the validation of the activity, reinforced Katy's desire to throw the necklace again, anticipating a similar response.

> Katy threw the necklace onto the floor. Sue picked them up and gave them back to Katy. Katy threw the necklace again and Sue again returned them. A throwing game began. (Observer notes 16.5.2016)

Katy was in control and, because of the sensitive response of her interactive partner, she is learning. This type of activity took time to develop with her but, once the game pattern was established, revealed depths in Katy's reasoning, problem-solving and anticipation, as shown in the notes below.

> Katy throws the beads intentionally in different directions for Sue to retrieve. (Observer notes 27.6.2016)
> Katy throws the beads sometimes intentionally to Sue and sometimes not. Teasing. (Video notes 7.10.2016)
> Katy taking the beads from Sue's hand. (Video notes 10.10.2016)
> Katy laughing and intentionally throws the beanbag away from Sue. (Video notes 1.11.2016)

These are key elements of the learning process; by a process of modelling, Katy learned from her interactive partner the essential aspects of interaction, that is, how to make the experience meaningful and fun for herself. The process developed from Katy tolerating a fairly passive interaction from her partner to initiating the interaction herself.

The documentary data revealed many aspects of Katy's learning and education. The Annual Review report described the programme of study she had followed, including the following mainstream subjects: Maths, Literacy, Science, History, Geography, RE, PE, Art, Music, DT and PSHE. Other subjects more specific to special schools and Katy, in particular, were Communication, ILS, Physiotherapy/Massage, Sensology/TacPac and Swimming. The support that Katy required to access education and learning was considered, together with additional considerations, as shown in the following extracts.

> Small group teaching. Weekly Physiotherapy, An IEP. Support from Speech and Language Therapy and Occupational Therapy

A range of different taste resources. Lunchtime support. OT and SALT time. Physiotherapy - individual and group sessions. Additional staff to support peer interaction.

A new continuing care assessment for Katy would be helpful. It is believed that Katy may now meet the criteria for a specialist learning support assistant. (G48)

All the subject teachers reported on Katy's effort in particular subjects as shown, for example, in extracts from her Maths report below.

This year Katy has taken part in a variety of measuring activities. She has examined long and short objects.

Other subjects include Food Technology and Swimming, as noted below.

With support, Katy has explored a range of food textures with her hands.
Katy has achieved floating on her back and kicking her legs on her back.

The report also includes comments about Katy's social and emotional development.

Katy enjoys the social aspects and is becoming more in tune with emotions of those around her, for example joining in with laughter at something funny.

Katy will reach out for an item she knows someone is going to pass to her.

The Annual Review Report included comments from health professionals who worked with Katy, as noted below.

It is lovely to see how Katy engages with the physiotherapy group.

The targets set for Katy by the school staff were similar in all curriculum areas, as can be seen from those set below.

To pass an item to a friend in a controlled way.
To push a Boccia ball down a ramp without picking it up and throwing it.
To hold an item in her hand for a short period.

To follow individual communication targets.
To develop the use of her DELL communication aid. (G13)

To imitate a sound vocally.

The targets reflect the objectives or outcomes from the statement or EHCP which are shown below. Objectives set an overall direction for learning, while targets are more specific, at an educational operational level.

Objective :
To be able to communicate with others and understand language so that she can make her needs known and follow simple instructions

Objective
To achieve social skills that enable her to establish and maintain positive peer group relationships within a small group

Objective
To improve her fine motor (G17) control so that she can use both hands to learn from the exploration of her environment

There were many aspects to Katy's educational provision and learning, as the data demonstrate. Through the Annual Review process, objectives and targets were set and resources identified to support learning. Katy learned mainstream subjects alongside activities specific to special schools and her in particular. At the same time, Katy was engaging in other learning. Every morning, I observed Katy being placed over a wedge with a tray of small objects, such as shells, placed within her easy reach. Katy would throw these things around her, and a teaching assistant would then pick them up and return them to the tray for the activity to be repeated. This would happen several times. Katy had learned that she should simply randomly throw the shells. Within the interactive session, this activity took on more meaning and became a game to share with another. Katy enjoyed this and developed social skills and confidence through this alternative type of learning.

4.4.3 Transition Planning

Transition planning begins in Year 9, the year Katy was in at the beginning of the data collection period, and involves preparation and planning for leaving school. The school hosts a transition planning meeting to which all relevant parties, including the young person, are invited. The documentary evidence comprises notes, statutorily required, of the meeting. Katy, however, was not present at the meeting. The initial questions

concerned whether or not she wanted to stay in education and which course she would like to follow. The responses made on Katy's behalf were as follows.

> Yes, Katy would like to stay in education but with an appropriate member of staff with her.
> Katy would like to do a sensory based course. (G43)

The family section is completed as if on the family's behalf but expresses their deep concern regarding the transition.

> Parents are very worried about her future and believe that she would benefit from 1-1 support, especially in a post-school environment.

The school records current health professionals' support for Katy.

> Katy will need support from the following professionals: Physiotherapy, Occupational Therapy, Speech Therapy, Community Nursing Team and Social Worker.

The sections concerning voluntary work and training were completed with a simple N/A. These options were obviously not considered for Katy. The form considers preparation for independent living and records the following response.

> Katy would benefit from a course involving real life situations to develop independence.

Attention was given to Katy's transport needs, identified as follows.

> Katy will need 1-1 escort on specialist transport. Currently her Mum is her escort because of her complex medical needs.

Consideration was given as to how Katy could participate in her local community and the help she required. The statements in this section did not really address the issues raised. Neither comment addresses how Katy will access community facilities as an adult. The final part recorded the further actions required to enhance and develop educational provision for Katy: more information on Katy's health issues and the need for her parents to begin to look at the post-school provision that may be suitable for her.

> Request a health report. Action. Deputy Head ASAP
> Visit post 16 provision. Action. Parents 2016-17

4.4.4 Health

The transition planning documents include the following statement made on Katy's behalf.

> Katy wants to be happy and safe. This involves having the support of someone who knows her extremely well and is able to support her complex medical and physical needs (G 12). She would like adequate support when she leaves school, ideally 1-1.

The following statements from the annual review documentation demonstrate the impact of Katy's health issues and her need for particular resources, such as a hoist to assist staff to move her with greater ease and comfort.

> The new hoist is working better. Katy is really engaged in activities. Her tolerance for handling things has improved.

Katy's current health issues while awaiting surgery impact on her education, as shown below.

> Katy is unable to stand as much as she needs as she is awaiting an operation on her ankle. It is currently very difficult for her to wear her splints.

Katy now requires oxygen when she sleeps and may need it if she sleeps in school, for example after she has had a seizure.

> Katy now needs oxygen at night. (G32)
> Katy also needs oxygen, if she sleeps during the day.
> Katy needs more time out of her wheelchair because of pressure sores. (G39)

Attention was needed to alleviate her pressure sores and the situations that may have exacerbated them, as noted above. Concerns regarding Katy's general diet are implied by the comment below.

> Can be very upset around food.

One of Katy's educational outcomes was very specific, designed to help her overcome difficulties with physical movement in a day-to-day context, as detailed below.

> To use her hand and body movements to help dress and undress herself.

The comments below were written at the beginning of the research with Katy, when I was getting to know her and beginning to realise the practical implications of her disability.

> Katy does not sit independently. I realise I do not know Katy at all. (Journal Notes 14.3.2016).

I became aware of the impact of Katy's health issues as the research progressed and I became predominantly concerned with issues relating to Katy's wellbeing within the research. Many of the sessions were mutually enjoyable and stimulating for both of us. My focus was simply not on the degree of Katy's disabilities, yet I made a note of caution, shown below.

> There are constant reminders of the impact of the range of Katy's disabilities, sitting, fits, vision. Yet it is so easy to forget these when things are going well. (Journal 6.6.2016)

At this stage, Katy and I were enjoying some very good sessions and Katy did not want each session to end. Our relationship was developing; this was perhaps a projection of my own positive feelings of acceptance by Katy. I was also becoming very aware of the trust that Katy was sharing with me and was cautious because I knew that I would not be able to continue the sessions in the long term. This highlights a substantial ethical dilemma around conducting research with vulnerable young people and the potential impact it may have on their mental health. Katy had so many physical health issues that it was easy not to give sufficient thought to her mental health, as is often the case for young people with PMLD. The following note reflects some of these thoughts.

> I must not get carried away. I must reflect upon the intensity of the interactive sessions for Katy. (Journal 20.6.2016)

I had a long discussion with the Music Therapist who posed the following question regarding my research with Katy.

> Is this research process helping the young people know themselves better? (Journal 22.6.2016)

This was an interesting question, yet difficult to answer. The interactive sessions provided an opportunity for Katy to develop the depth of her communication with another person and for this communication to be valued and reciprocated. Katy may thereby have been able to discover aspects of herself that she may not previously have had the opportunity to experience within the school setting. These could enhance her sense of wellbeing and, ultimately, help her to influence her future life.

On one occasion, Katy arrived at our interactive session appearing rather listless. I was not sure of the reason for this. The session went ahead as planned and I made the following notes in my journal afterwards.

> Katy very quiet today. She tried to participate but chose to sit and hold my hand and look intently at me. At times I felt I wanted to give her a hug. At the end of the session the TA said that Katy had an absence/twitch five minutes before she came to the session. I must consider that impact of health upon Katy. (Journal 20.6.2016)

Following deeper reflection on Katy's attitude in the session and the subsequent comments made by the teaching assistant, I made the following notes.

> There is a pressure for Katy to conform, however she is feeling. If I had a fit, would I feel like conforming to the noise and activity of the classroom? I do not know the answer to this question, I can only surmise my feelings. My initial thoughts are that I would want quiet time to recover.

Katy's reactions in the interactive session may have indicated a desire to be quiet and reflective. In the classroom setting, I have observed a general desire from staff for everyone to actively and happily engage in activity within their capability. The tone of the teaching assistant's comments was that Katy would be 'jollied along' when she returned to the classroom. Katy does not have the skills to communicate that she needed quiet time in a setting where the young people are constantly encouraged to be 'happy'. This atmosphere could impact on a young person's emotional wellbeing. The need to respond and conform to the desire of significant others to be in a constant state of happiness will be discussed further in Chapter Five. Throughout the case study, the subtle effects of chronic health issues such as Katy's epileptic seizures unfolded. It is important to provide the correct support for Katy so that she is comfortable and can use whatever movement she has to maximum advantage.

4.4.5 Impact of Others

From the data, it emerged that those people involved in Katy's life had, in various forms, a significant impact on her life and the situations in which she found herself. When Katy is in a situation where the other person responds with patience and sensitivity, her confidence develops. This was demonstrated in the interactive sessions, which developed her desire to touch and to sustain touch, as noted below.

> Katy kept her hands on Sue's hands when Sue touched Katy's hands. (Observer notes 17.3.2016)

The interactive, supportive atmosphere encouraged Katy to listen.

> Holds Sue's hand, keeps head down with her chin on her chest, listening to Sue's voice (Observation notes 20.6.2016)

As the interactive relationship developed, so did Katy's confidence, so that she began to reach out to the other person, as noted in 4.4.1.

> Katy reached out to Sue and pulled her close to herself. (Observer notes 20.6.2016)

If the interactive partner responds to the activity, endorsing it and giving it meaning, it can develop into a meaningful interactive activity. From the above example, it is possible to see that the response to the throwing and the validation of the activity reinforced Katy's desire to throw again, anticipating a similar response. Katy was in control because of the sensitive response of her interactive partner.

> Katy threw the necklace onto the floor. Sue picked them up and gave them back to Katy. Katy threw the necklace again and Sue again returned them. A throwing game began. (Observer notes 16.5.2016)

It is a vital part of any interaction that each person has sufficient confidence to reach out to the other. Interaction is essentially about sharing and, in order to share, each person must be open and inviting towards the other. Through the interactive sessions and incidental comments from TAs, I became aware of the influence of familiar attitudes and made the journal note below. This clearly indicates that the TA simply accepted that having minor seizure activity was normal for Katy and so did not consider the impact it had upon Katy.

> Katy found it very difficult to interact today. She kept trying. TA said Katy had seizure before I arrived. Finished session early. Katy obviously struggling. TA comment Katy would be fine in the classroom where lots of activity. I thought if someone has had a seizure do they want to be in a noisy classroom? Is this pressure to conform despite Katy having had the seizure and clearly feeling bewildered. (Reflective Journal 17.11.2016)

The documentary data demonstrated that many people had a significant impact upon Katy's life. In the learning and education theme, there is evidence of judgements and future targets being set for Katy with no input from Katy herself. The transition planning meeting happened without Katy present. Opinions were voiced and decisions made about Katy's future without Katy being present or having any influence.
It would seem that other people have a significant impact on Katy's life.

4.4.6 Thoughtfulness

On a few occasions, Katy used gestures that were difficult to interpret. Sometimes it appeared that she was taking time to think, as demonstrated by the notes below.

> Katy started to rub her eyes when the session was about to end. (Observer notes 6.6.2016, 13.6.2016).
> Katy held her head down. (Observer notes 20.6.2016)

It is possible to think that Katy was rubbing her nose because she was thinking about the end of the session, particularly as it happened on two consecutive sessions. When she held her head down, that would seem more explicitly to indicate that she was taking time out from the session for some reason.

There were times when Katy listened attentively to specific things around her, as described below.

> Katy listen to rain stick hands on chest. Still make no sound. (Observer notes 11.7.16)
> Quiet reflection. Katy can't reach beanbag. Stop to think. Eventually reach beanbag. (Video 7.10.16)
> Katy stop interaction, sit quietly then start blow raspberry (Video 1.11.16)

Katy seems to be intentionally stopping to think and perhaps have a conversation with herself. From these observations, it is clear that Katy is taking time to think things through, to solve problems, for example finding and holding the instrument. When she stops engaging with the current activity and introduces a new activity, raspberry blowing, she is taking control of the situation. She is also using this quiet reflective time to make decisions, for example, deciding which way to throw the beanbag as part of the interactive game that she has initiated. The data suggests that listening is important for Katy; it may be that she is not only listening to extraneous things but also to her own thoughts. Raspberry-blowing is one of Katy's particular sounds, perhaps she is talking to herself.

On one occasion, Katy arrived at the session appearing rather listless. She tried to interact, but it seemed a great effort. Eventually, we simply sat together quietly enjoying our common space. Katy clearly demonstrated that she did not have the energy or inclination to interact; she simply wanted to spend empathetic time with me. At the end of the session, I discovered that she had had a seizure prior to coming to the session.

Under the circumstances, the way Katy conducted herself in the session seems entirely reasonable, yet it would appear from the conversation with the T.A. that Katy would normally be expected and encouraged to join in the class activities. Following this incident, I made the following comment in the research journal.

> There is a pressure for Katy to conform however she is feeling. If I had a fit, would I feel like conforming to the noise and activity of the classroom? I do not know the answer to this question. I can only surmise my feelings. My initial thoughts are that I would want quiet time to recover. (Journal 17.11.2016)

This indicates that a deeper, thoughtful relationship is potentially developing.

> I think Katy and I are beginning to inhabit a common space in our interactive sessions. (Journal 16.5.2016)

Yet, on other occasions, I too query why Katy does not seem her usual outgoing self, indicating the pressure on Katy to be outgoing and happy, rather than accepting her different moods and introspections as indicated below. The implications of these thoughts will be discussed in Chapter Five.

> Katy was not interacting with her usual enthusiasm today. Why? Was she bored? Was it because we had a different TA as research assistant? (Journal 23.5.2016)

Katy demonstrated on several occasions her need and ability to behave thoughtfully, to think through future actions, to reflect upon how she was feeling and, as is common with everyone, to have her private thoughts.

4.4.7 Concluding Comments – Katy Case Study

Katy's case study demonstrates very clearly how young people with PMLD can, if given the opportunity, take the lead in a relationship. They can introduce a tremendous amount of fun and sharing in an equal relationship. They also need time for personal reflection. Katy's physical health issues are significant and have an impact on her daily life. She is totally dependent on other people to attend to her care and on their support with many other daily activities. As the data demonstrates, there is a risk that in focusing completely upon Katy's physical needs, her mental health may be overlooked. Throughout the interactive sessions, Katy has demonstrated that she is a sociable yet thoughtful, sensitive young woman. This aspect of her personality can be compromised in a busy environment.

4.5 Concluding Comments – Case Studies

The data raised a range of issues, some of which I anticipated from my professional experience. These include issues relating to communication, health, transition, education and learning. Other issues arose that I did not anticipate. The findings have revealed aspects of the previously mentioned points but in much greater depth than I had anticipated. For example, Katy revealed a depth of thought and anticipation that I had not expected. Significant attention was paid to physical well-being, but relatively little given to the young people's mental well-being. Furthermore, the impact of a wide range of people upon each young person's life and development was more evident than I had anticipated. The detailed, deep knowledge of each young person that has been revealed by the case studies has increased my awareness of the need to approach each young person as an individual, without preconceived information or notions, allowing them to reveal themselves just as any other person would. Throughout the analysis of the data, I have become aware of the explicit and implicit influence of government statutory guidance on the education and transition process. The explicit influence is exerted by the statutory documents and the implicit influence in the way those documents are interpreted by various stakeholders in order to comply with and make sense of them, such as completing a document as though the young person has expressed these answers, without allowing the young person to do so.

The analysis of the data identified two themes common to all three case studies:

- Communication
- Education and Learning

Two themes were common to the case studies of Linda and Katy:

- Transition
- Impact of others

One theme was common to the case studies of Harry and Katy:

- Health

Other themes that emerged were specific to individual case studies. These themes related to deeper aspects of each young person.

- For Harry, the following individual themes were identified: empowerment, emotion and perception of others.

- For Linda, the following individual theme was identified: things that are difficult to understand.
- For Katy, the following individual theme was identified: thoughtfulness.

The young people involved in the case studies present many complex issues. They offer to challenge to society as to how they can be included with respect and dignity, yet receive the care and support that is essential for their wellbeing. The issues identified above will be discussed in greater depth in Chapters Five and Six.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

Before considering the themes that have emerged throughout the data, it is worth remembering the genesis of the project. It emerged from a desire to understand and develop the contribution that young people with PMLD can make to their post-school planning process and was motivated by my observations as a practitioner in special education. Particularly in my role as headteacher, I was aware that young people with PMLD did not have access to the appropriate resources to enable them to influence their post-school planning process, despite government rhetoric that espoused participation in the planning process for all young people, as noted in Literature Review 2.7. The underlying principles of social justice, as discussed in Literature Review 2.9, have underpinned the work for this project.

The core focus of the project is explained in the Introduction (1.7) and specifically identified in the research question below.

How can young people with PMLD influence their own post-school transition planning process?

The analysis of the data revealed a variety of issues, some of which could be anticipated. Those aspects that were anticipated were those that I had observed and noted through first-hand experience as a practitioner. These included communication with young people with PMLD, the transition process, stakeholder engagement with transition and the availability of post-school opportunities. Some outcomes of the analysis, such as the usefulness of Intensive Interaction, endorsed elements that had been identified through the literature. However, I had not given significant consideration to other issues prior to the analysis of the data, such as the difficulty that young people with PMLD experience when trying to express emotion and inner thoughtfulness. Some themes are common to all three case studies: communication, education and learning. Other themes emerged from two case studies: transition, health and the impact of others. Some themes

appeared in only one case study: things that are difficult to understand, empowerment, emotion, thoughtfulness and perceptions of the young person.

5.2 Communication

Communication was identified as a core theme for the research and has remained so throughout the research process. Understanding and developing communication with individual young people lies at the heart of this research.

Many communication systems for this group of young people are based on signs and symbols, representing the words used by verbal communicators. These are often taught in unrealistic situations, omitting the vital elements of social and cognitive aspects of communication (Imray & Colley, 2017), as demonstrated by Linda's use of her communication aid (Findings 4.3.1). This approach provides a controlled method of communication. The young person can only use the symbols or signs with which they are provided. They may want to communicate something in their experience that is not included in the system provided, as was the case when Linda tried to request something using her communication (Findings 4.3.1). This type of communication limits what the young person can express to the words or symbols put into the communication device by a member of staff. In this sense, the member of staff controls what the person is able to communicate. The young person is rarely consulted as to the choice of words or symbols put into their communication device (Bryan, 2018).

Functional communication is frequently identified in education planning for young people with PMLD in the form of longer-term outcomes and short-term targets, as noted in Harry's case study (Findings 4.2.1). There were instances in the findings when communication targets were set in more realistic terms: Katy's target was to use her DELL communication aid to make choices (Findings 4.4.2). In this situation, the choices available to Katy were still limited by what had been programmed into the machine by a member of staff without consultation with her. Linda had a target to use her communication aid, supported by a member of staff, to make choices at lunchtime (Findings 4.3.1) in an example of using a communication target in a realistic context. The choice was limited only in the same way as for everyone else, to the food on offer. Within education, other aspects of functional communication are identified. An aspect of

communication identified in Harry's case study (Findings 4.2.1) is his use of eye contact. This can be identified as a general functional communication skill that is important. Katy was seen to demonstrate that she was emotionally more in tune with others when she showed excitement in anticipating her turn (Findings 4.4.2).

Communication is a social activity, enabling us to form relationships with other people (Goldbart & Coupe O'Kane, 1988). It has a broader interpretation; in recognising that its function is for two people to co-ordinate actions, and work together through ongoing responses to each other and their situation, this communication respects and nurtures the communication of young people with PMLD (Goldbart & Ware, 2015). The situation in which the communication occurs is recognised as important to the development of both functional and social communication; the two are integrated. The situation is considered holistically to nurture communication that is effective for both participants.

Effective communication with young people with PMLD requires ingenuity and deep understanding. Intensive Interaction provides a holistic, total communication approach that enables the young person to communicate in their own idiosyncratic way (Hewett et al., 2012). Harry demonstrated this type of communication when he threw his head back, laughing, slapping his thigh and shaking his whole body. On another occasion, he grabbed the interactive partner's hand and showed his lack of interest by looking beyond that person and out of the window. These are communications peculiar to Harry, showing his emotions and reactions to things and people (Findings 4.2.1).

The analysis of the data from the pilot study revealed the need to identify a means of communication with young people that enabled them to express themselves directly to the researcher (see Methodology 3.2). I needed to find a method of communication that would enable the young person to assume control of and influence the research process. Intensive Interaction was identified as one such method: it could be used to provide the opportunities necessary to meet the criteria of the research process (see Methodology 3.2, 3.4)

The literature related to Intensive Interaction (Literature Review 2.6) described this method of communication exchange in sufficient detail that others could use it. This was

useful as it provided clear guidelines that enabled the development of Intensive Interaction from an education-based use to its innovative use as a research tool. Some studies were written like a manual (Hewett et al., 2012) while others described individuals and the outcomes of the communication exchange relationship, often in a therapeutic context (Caudwell, 2006). As detailed in the literature review, guidelines regarding Intensive Interaction were followed during the interactive sessions, notably the underlying values of mutual respect, following the young person's lead, providing a space for the young person to feel secure to be themselves and a collaborative sympathetic environment. As each young person relaxed into the interactive session, they revealed emotional aspects of their personality and aspects they found difficult to express. This was in some respects similar to what may happen in a therapeutic situation, as noted in the literature review. In a therapeutic setting, however, issues of confidentiality would arise which were not present in the interactive sessions which were open-ended sharing activities. Intensive Interaction was chosen as a method of mutual communication that could be adapted as a research tool to enable the authentic participation of young people with PMLD.

Given time and a responsive communication partner, the young people began to initiate communicative activity. For example, the researcher sat quietly beside Katy. Katy listened and eventually began moving her eyes from side to side as a very tentative form of communication. This progressed in a future session to a point at which Katy reached out to touch the researcher's arm (Findings 4.4.1). The young people enjoyed these situations and were keen to develop aspects of the communication, such as sharing activities. The interactive sessions showed the joy and delight that can be experienced by young people with PMLD when engaged in interactive communication. Linda was keen to share her Christmas Carol book and was happy to share the experience of making some form of music with the researcher (Findings 4.3.1). Katy shared a game of throwing beads (Findings 4.4.1).

The young people were, thus, able to share aspects of their inner thoughts. Space must be created where they can express their inner selves and the issues important to them in a way that they feel confident about (Johnson & Walmsley, 2010). The education system emphasises external, observable communication, which may enable young

people to make choices but does not acknowledge their need to be able to communicate deeper inner thoughts and feelings (Weldon, 1986). Katy demonstrated her inner thoughtfulness by deliberately taking moments of quiet reflection, often followed by specific actions (Findings 4.4.1). Linda sat quietly during several sessions thinking about how to use her communication aid to request the piano on the iPad. Eventually, through this thoughtful behaviour, she was able to achieve her desired outcome (Findings 4.3.1).

The analysis of the data revealed that in a conducive environment young people with PMLD could take the lead in communication exchanges. Linda was keen to lead activities when she was in the security of her home environment. She introduced activities such as banging a drum, throwing a soft ball and stopped the activity and waited for me to join in (Findings 4.3.1). The environment needs to be comfortable for each young person. I became aware of this in relation to Katy when I noted in my journal my growing awareness of the impact of Katy's disabilities and the need to be constantly aware of this (Findings 4.4.3). Particularly for Harry and Katy, their health issues were significant and needed to be considered in all situations (Findings 4.2.3 and 4.4.3).

Through the application of the principles of Intensive Interaction, the young people in the project felt listened to, not in a conventional way but through their behaviours and expressions (Imray & Colley, 2017). Analysis of the data revealed instances of such behaviour: Harry hung his head, not wanting to communicate in the initial session but in later sessions he smiled and reached out to touch my hand (Findings 4.2.1) When given an iPad, Katy pushed it away indicating that she did not want it. In some sessions she vocalised a 'La, La' sound that was meaningful to her. Within the session, this was echoed back to her and reinforced as meaningful communication (Findings 4.4.1).

Interpretation is an important part of communication and this research has identified many areas where interpretations vary. The interpretation of young people's behaviour is variable. When I first met Harry, I was warned by staff at the school that he was the most difficult young person to communicate with. Harry's behaviour at our first session was challenging: for a long time, he hung his head and refused to look at me, as

described previously (Findings 4.2.1). After a session when Katy was very quiet following an epileptic seizure, the TA remarked that when Katy got back to the classroom she would cheer up with the classroom activity around her. This remark demonstrated a lack of appreciation of how Katy might be feeling after a seizure (Findings 4.4.5).

The interactive data for Harry was analysed from the perspectives of the researcher and Harry himself (Findings 4.2.1) in order to see what difference the varying perspectives would make to the analysis outcomes. The majority of sub-categories remained the same but with different names. From Harry's perspective, a sub-category 'attracted attention' emerged; from the researcher's perspective, this was 'mutual contact/engagement'. The sub-category 'I am not sure' in the analysis from Harry's perspective did not occur in the analysis from the researcher's perspective. This category from Harry's viewpoint seemed to indicate a sense of thoughtfulness, something that is not often referred to in relation to young people with PMLD in a school setting. The analysis was conducted by someone from a school-based background who may have brought that lens to the analysis, not seeing Harry's thoughtfulness as it emerged when the data was analysed through Harry's lens. The different language used for the categories when approached from the different perspectives demonstrated a different value of the activity. When analysed from Harry's perspective, the language was more empowering for Harry. The researcher named a sub-group 'repetitive behaviour' whereas Harry's perspective identified a category of 'I am doing my own thing'. The difference is subtle but worthy of note. The researcher's identification of repetitive behaviour has a slightly condescending approach, not valuing the activity in itself. The analysis from Harry's perspective reveals a young person who is confidently doing something that he enjoys. As demonstrated above, behaviour can be interpreted as repetitive and, by implication, having little value, yet it is meaningful for Harry and should therefore be acknowledged with respect. Linda displayed behaviour that was challenging to members of staff when she threw things around the classroom. She displayed behaviour that was disturbing for her parents when she became tearful and her parents did not know the cause. In both these instances, the behaviour had meaning for Linda but was difficult and challenging for those around her (Findings 4.3.1, 4.3.2).

The interpretation of a young person's communicative behaviour has consequences for the way other people react to them and the atmosphere in which they live. Different interpretations in different circumstances can be confusing for the young person. When Linda transferred to college, the lunchtime staff interpreted her behaviour as meaning that she needed constant verbal and physical prompts to eat her lunch. At school and home, she eats slowly but with no prompting (Findings 4.3.1).

This situation manifests itself in different parts of a young person's life: at school, home, in the wider family and social situations and within the wider community (Simmons & Watson, 2014) as, for example, with Harry, who appeared withdrawn and almost anti-social at school, whereas Harry's mother said that at home he communicated his enjoyment of a range of activities, including watching television, going to the cinema and going for walks. She said that he loves cats and they have five at home. Following a visit to Harry's home, I recorded in the journal that I thought Harry was much more relaxed at home than when I had seen him at school (Findings 4.2.5, 4.2.6). Linda's parents said that she was not at all pro-active in her communication at home but, at school, when I said that the interactive session had finished, Linda promptly got up and walked out of the room, communicating to me that she was ready to leave (Findings 4.3.1).

Young people with PMLD can often be dismissed as non-communicators because of a narrow understanding of the purpose of communication. The communication of young people with PMLD has been influenced by cognitive-developmental approaches (Literature Review 2.6) which can limit perceptions of the communicative ability of young people with PMLD. It can be assumed that, due to their cognitive impairments, they will not be able to communicate. Young people with PMLD are expected to function in a world dominated by skilled communicators. If they cannot communicate in a way that is easily understood by skilled communicators, they tend to be excluded (Barber, 2007; Literature Review 2.6).

5.2.1 Communication in Transition Planning

The different emphasis demonstrated by the analysis from different perspectives reflects the transition planning process. The transition planning process and activities can be interpreted from the perspective of those interested parties who are skilled communicators, potentially excluding those who are less skilled communicators (Barber, 2007) and failing to see the meaning of idiosyncratic communication behaviours from the perspective of the young person (Porter & Lacey, 2005). Katy was not present at her planning meeting. In her absence, it was recorded that Katy would like to continue in education. Her parents, who play a vital role in Katy's life, expressed their anxiety about her leaving school and their desire for her to have 1-1 support wherever she goes, although she does not have this support at school (Findings 4.4.3). It would seem that parental anxiety outweighed Katy's need to develop independence and personal autonomy. While this is understandable, the post-school plans of most young people are not determined by their parent's anxieties.

Excluding the views of young people in their transition planning can be interpreted as a lack of consideration and value for the young person. The people in charge of the process do not take the time to know the young people. People often speak for young people with PMLD assuming they cannot communicate; for example, Linda was present at the combined annual review and transition meeting but did not contribute. Other people in the meeting spoke on her behalf and there was no evidence that she had been consulted. At times, the record of the meeting stated that Linda would take particular actions in preparation for leaving school. At other times, comments were recorded as though Linda had said them, although the vocabulary and tone were too complex for Linda to have communicated herself (Findings 4.3.4). Katy was not present at her planning meeting and statements were made on her behalf to the effect that she would like to stay in education and follow a sensory-based course. Once again, there was no evidence that Katy had had any input into what was said at the meeting (Findings 4.4.3).

The function of communication can be interpreted as an exchange of information, as mentioned in the opening paragraphs of this section. It is probably this emphasis on functional communication that prevents the young people in the case studies from having any voice in their planning meeting. Even when communication is considered as

merely exchanging information, it is informed by thought. It is considered difficult for young people with PMLD to fulfil this interpretation of communication due to their cognitive and other complex difficulties. Merleau-Ponty (1962) considers the relationship between thought and communication, and it is important to acknowledge this relationship in the lives of young people with PMLD. Within the interactive sessions, examples were seen of the young people thinking before communicating. For example, Linda exercised considerable thought to eventually use her communication aid to get what she wanted (Findings 4.3.1). The alignment of thought and communication can reflect the lived experience of young people with PMLD, as discussed by Merciea (2013). In the example cited above, Linda was demonstrating and reflecting upon her lived experience. She had previously enjoyed playing the piano on the iPad and wanted to experience it again. Linda was able to demonstrate her ability to use thinking to solve a problem and influence her own choices in the situation described.

5.2.2 Transition and the Inner Thoughts and Feelings of Young People with PMLD

To try to understand the thoughts and experiences of a young person with PMLD, Kittay (2019) says that to value a person it is important that time is given to get to know that person. Kittay, who has an adult daughter with PMLD, does not view the impairment as the problem, but the response of others to it. People find it difficult to connect with these young people yet, in order for young people with PMLD to connect and communicate with other people, they must have opportunities to do so (Ware, 1996). Kittay recognises that other people will always need to help and support young people with PMLD but believes this does not have to reduce the young person's sense of self-sufficiency. Within a supportive relationship, the young person has agency and can contribute to the development of the other person. This view concurs with that of Mercieca (2013) who discusses the challenge of the silence that young people with PMLD offer, a time to re-think how we communicate and reflect on the power of silence in our relationships and communication. Goldbart and Coupe O'Kane also recognise the importance of the need to communicate with others.

The young people's responses within the sessions endorsed the view that young people with PMLD enjoy being listened to when given the freedom to express themselves in a way with which they are confident and comfortable. The data demonstrate that young

people open up when in an environment where they feel listened to, as mentioned previously in this section. The young people have been listened to, not in a conventional way, but in a way that is conducive to them. Through the sessions of Intensive Interaction, the young people communicated things about themselves that are important to them, that they may not be able to express in more functional communication (Findings 4.2.1, 4.3.1 and 4.4.1).

5.2.3 Recognising Inner Thoughts and Feelings of Young People with PMLD

The research identifies a deeper type of communication enjoyed by the young people in the case studies which enabled them to share their inner selves, a facet of young people with PMLD that is often ignored, as noted in the section on Thoughtfulness in Katy's case study (Findings 4.4.6). Communication for young people with PMLD is as multi-faceted as for any other member of the population. This needs to be acknowledged and respected, with those around them responsive to whatever form of communication the young person uses to express their desires and feelings. By listening to each individual's personal way of communicating, each young person revealed that they had difficulty expressing their emotions and having this expression of their emotions listened to. They were able to convey their personality, showing whether they had extrovert tendencies such as Katy or more introverted tendencies such as Linda (Findings 4.3.1, 4.4.1). Underlying personal attributes were conveyed, including thoughtfulness, humour, persistence, gentleness and initiative. These attributes can be overlooked in more formal, less personalised settings.

There are realms of the young person's inner self and identity that are not acknowledged and this denies them the opportunity to share this inner world with other people. The interactive sessions revealed their attributes and difficulties; the failure to acknowledge and respect these represents a considerable loss for everybody. In a sense, the whole community is being denied their contribution of reciprocity, as identified by Kittay (2019).

5.3 Education and Learning

Access to education for young people with PMLD has changed over time and has been influenced by society's perceptions and understanding of this group of young people. At

the start of the twentieth century, young people with learning difficulties were defined as Idiots and Imbeciles under the Mental Deficiency Act 1913. In the Education Act 1944 they were deemed uneducable; the 1959 Mental Health Act recognised that they benefit from education but decided this was to be delivered in training centres run by health professionals. It was only in 1970 that young people with PMLD eventually became the responsibility of the Education Department and all pupils were deemed to benefit from education. Subsequently, opinions have developed regarding how young people with PMLD should be taught and what they would benefit from learning.

The curriculum framework for PMLD pupils has varied since 1970, with the behaviourist approach very dominant during the latter decades of the twentieth century. This emphasised the teaching of simple tasks and communication in a very structured way with extrinsic rewards built into the delivery of education (Simmons & Watson, 2014). In the final decade of the twentieth century, continuing into the twenty-first century, more responsive approaches to teaching young people with PMLD have developed (Literature Review 2.4 & 2.6).

The relationship between education and care has had and continues to exert a strong influence upon the education and learning of young people with PMLD. The medical needs of the young people can overwhelm the perceptions of their other needs, including their cognitive and emotional needs, as demonstrated by Bryan. The attention given to issues of care of the young person within the school environment can create tension between members of staff who have different priorities for that young person, as seen in Harry's case study, and can in turn impact upon the young person's educational opportunities and learning experiences. The influence of models of disability has affected approaches to the education of young people with PMLD. The strong influence of the medical model, focussing on the alleviation of the physical effects of a person's disability as paramount, and the social model of disability has led to the adaption of the environment in which the young person is educated towards inclusive settings.

In the annual review reports for the three case studies, there were various interpretations of achievement. Harry's case study refers synonymously to achievement

and responding to an activity, implying they are similar, as noted above. Linda's Annual Review states what she has been able to do and the level of support she required. Katy's Annual Review records what she had participated in, possibly interpreting this as an achievement, although this is not clear (Findings 4.4.2).

The understanding of achievements for pupils with PMLD can be arbitrary and is susceptible to varied interpretation by parents, teachers, medical professionals and support staff (Mercieca, 2013). Katy and Linda's achievements are practical and observable; Harry's are more reflective but still observable. These achievements are individual, reflecting a single person's achievement, as discussed in Findings 4.2.2, 4.3.3 and 4.4.2. It is possible to view achievements through a different lens, through a lens of co-operation. Achievement can also be experienced through reciprocal co-operation (Simmons & Watson, 2014). Harry is achieving by co-operating with another person (Findings 4.2.2).

Intensive Interaction (Literature Review 2.6) provides an opportunity for reciprocal co-operation and enables learning to take place. This was demonstrated in the case studies, where Linda learnt to use her iPad communication aid to express what she wanted, Katy learnt how to develop the throwing beads game and Harry learnt how to initiate communication through touch (Findings 4.3.1, 4.4.1 and 4.2.1). Within this situation, the young person feels in control, comfortable and secure. They feel supported in a relationship of reciprocal learning. Within the interactive sessions, the young people's profound difficulties were acknowledged but were not seen as an impediment to meaningful, rewarding and enriching experiences. In many circumstances, an over-emphasis on the person's disability can mask and impede their potential development. The approach of attending to the person and supporting them with their disability can be perceived as the capability approach to disability (Literature Review 2.9). The application of Intensive Interaction techniques can reduce the effect of young people's disabilities, emphasise their capabilities and enhance their ability to participate and achieve. Linda and Harry demonstrated with confidence their developing ability to share during the interactive sessions. Harry passed a toy to me and Linda was happy for me to join her in singing along to a Christmas carol (Findings 4.2.1, 4.3.1). Both these activities were achievements for these young people who usually did not have the

confidence to engage in sharing activities. The Intensive Interaction sessions demonstrated that, with the right support and in the right environment, the young people were able to function with greater confidence and autonomy and to contribute in a meaningful way. The young people and those around them can be challenged to think ambitiously (Bryan).

The language used in the planning and recording of young people's learning can influence the form of the education received and this is particularly true of the language in government documentation. The change, from a language of objectives in the statement of SEN to outcomes in EHCP, means that education and learning become more sharply focused. Objectives within the SEN Statement were over-arching, without specific detail, whereas the outcomes in the EHCP align to the targets that are set within schools for individual pupils and seek to achieve identifiable observable changes within the young person. The documentation for Katy exemplifies the change from general objectives to specific outcomes (Findings 4.2.2). This governmental language also influences the transfer of educational information at the point of transition from one education provider to another. This point will be developed thoroughly in the following section.

5.4 Transition

The transition process for young people with PMLD is complicated for many reasons. It is acknowledged that this group of young people have an ongoing need for care to enable them to have their basic needs met, such as the need to be fed and their personal care attended to (Strnadova & Evans, 2013). This ongoing need for care requires detailed information to be passed from one organisation to another and substantial anxiety, particularly for parents and school staff, surrounds the accurate transfer of information, affecting the individual care of the young person. Some of this anxiety is understandably related to letting go of previous trusted organisations and relationships. Some are caused by the different values and ethos of the transfer organisation. When I fed back to Linda's mother the observations I had made regarding Linda's reduced use of her communication aid at college, Linda's mother had suspected this was the case as the battery very seldom needed charging at the end of the day,

whereas at school it had always needed to be re-charged, as illustrated in Linda's case study (Findings 4.3.4).

Throughout the transition process, there is a common desire to provide opportunities to develop the full potential of young people with disabilities. The aspirations in the current planning process are based on articles within the Convention on The Rights of Persons with Disabilities (UN 2006). The contents of the Convention are optional, and countries may sign up to them, but they do lay down an expectation of how disabled people should be treated. One expectation concerns participation. Many prerequisites affect a young person's participation in their own transition planning. The need for a wide variety of accepted communication and freedom of expression for young people is acknowledged but the transition planning in two of the three case studies did not demonstrate that the young people benefitted from this acknowledgement. The two young people were not present and neither had any means of communicating their thoughts into the planning process. With the absence of their voice, other people spoke on their behalf as they saw fit, as can be seen in the transition section of the two case studies (Findings 4.3.4, 4.4.3).

The young person needs to have preparatory experiences that prepare them for the planning process. In the course of the education process, there are very limited opportunities for young people with PMLD to experience the consequences of their choices (Dee, 2012) and, in many circumstances, they are not afforded the opportunity to make choices. Without this prior experience, it is very difficult for the young person to comprehend the fundamental purpose of the transition planning process (Mansell et al., 2012). A government may believe that by passing legislation it is creating a uniform process, but in practice, this is not the case. The analysis of the data revealed different understandings of participation. According to government legislation, the young person and their parents must participate as fully as possible in the decision process (SEN Code of Practice, 2015). There are a variety of ways of understanding the terms within this legislation, as demonstrated in the case studies. Katy, for example, was not present at the meetings; Linda was present but all the decisions were made by other people: health staff, school staff and her parents (Findings 4.3.4, 4.4.3). The literature confirms the experience of the young people in the case studies (Dee, 2006, Jacobs, 2018,

Rodriguez, 2017). The planning documentation is addressed to the young person, asking them about their wishes for the future, in accordance with government legislation that states that all planning meetings must be person-centred and involve the young person (SEN Code Practice, 2015). Only one of the young people in the case studies, however, was present at the meeting and other people answered questions on behalf of all three young people, with the views of other significant people represented on a variety of issues. For Linda, other people answered whether she would like to stay in education, what support she would need in the community and how she would like to develop her skills (Findings 4.3.4). The questions asked of Linda were too complex for her to understand and respond to but, because completion of the form is a statutory requirement, other people answered on her behalf.

The individual interpretation of an institution can deny young people access to influence issues important to their future. The young person has no means to challenge this situation unless they are fortunate enough to have a very strong advocate who understands them, takes the time and explains to others the young person's needs (Lyle, 2018). The implementation of government guidelines and requirements can create additional stress for those involved in the planning process. The planning process, as identified by government, provides a broad-brush approach for all young people with SEN and disabilities. It does not address the intricacies involved for young people with PMLD or acknowledge the effect of differing institutional funding streams, ethos and values.

The function of the transition documentation is to provide a smooth, person-centred transition for each young person with SEN. The analysis of the data revealed that this was not the case. The documentation for Linda's transition did not address the detail of Linda's transition to college (Findings 4.3.4). It identified only that there was a place available, with funding and that Linda would have the support she required. This is the crucial element because a detailed understanding of Linda is vital to provide the support she requires. Data collected from two follow-up visits to the college revealed that, in some instances, Linda was being provided with too much 1-1 support, inhibiting her progress. In other instances, she was being given insufficient guidance and challenge (Findings 4.3.4).

Much of the formal transition planning procedure focuses on external, extrinsic aspects of transition, such as identifying a placement, funding, transport and the transfer of individual care procedures and requirements. There are other very significant aspects of transition for any person moving from one situation to another. It is particularly important to acknowledge and understand the internal thoughts and feelings of the participants when considering the transition of a young person with PMLD. The relationship between the school and family is vital, yet it can be precarious at times of transition. Transition from school is very significant for families of young people attending special schools. The school has often provided advice during difficult times and has been a sign-posting agent to other resources, the focal point for other services such as health care. Families can experience a great sense of loss and insecurity when approaching the time of transition. Young people with PMLD can exhibit behaviours demonstrating they are relaxed and comfortable. It is difficult to establish what sense of belonging these young people have and, therefore, their sense of loss at leaving school (Strnadova & Nind, 2019).

In order to address the impact of potential loss and insecurity, it is useful as part of the transition planning process to consider how the young person behaves in a variety of settings (Simmons & Watson, 2014). Transition is a process of changing to different settings and environments; at its heart should be a fundamental respect for a young person's autonomy (Mercieca, 2013).

There is frequently a lack of clarity surrounding the definition of keywords and phrases. It is assumed that those involved in the transition process have a common understanding of its key elements, but confusion in definitions and interpretations has a considerable impact on the young person. This is particularly important at the point of transition from one organisation to another, as was evident in Linda's transition from school to college (Findings 4.3.4). For young people with PMLD, the notion of support is frequently used generically, with no precise definition. With a clear understanding of the support Linda required, inconsistency in her transition may have been avoided.

Those contributing to the transition planning procedure are significant stakeholders in the transition process for each young person. Each stakeholder has a different understanding of the function of the documents associated with transition (Dee, 2006; Strnadova & Cummings, 2017). In many respects, the school professionals are gatekeepers of the documents. Other significant professionals, such as health professionals, contribute but do not have the ownership that the school has. The parents, unless they are very well-informed, are dependent on school staff to manage and record the process. This situation is, in many respects, perpetuated by whatever system is in place. The family is often at the mercy of powerful professionals who may have future placements in their gift, as was evident when Linda's parents were preparing for a review meeting (Findings 4.3.4). It is possible for the young person and their family to feel that the transition process is imposed upon them because their voices are not heard or attended to within the planning process. Other stakeholders can have differing views on what is best for the young person, and those most directly affected by the transition feel overwhelmed (Jacobs et al., 2018).

Transition planning decides the future circumstances of a young person and provides an opportunity to focus on the future quality of life for the young person (Male, 2015). Quality of life is open to interpretation and is often influenced by circumstances. Identified quality of life indicators include basic health, care, activities, space, social interaction and stimulation (Jacobs et al., 2018) Slightly different indicators apply for people with PMLD in terms of functional, personal and social indicators, including material and emotional wellbeing, interpersonal relationships and self-determination (Schalock & Alonso, 2012). Social indicators are explicit and easier to evaluate but the psychological and personal indicators are difficult to assess, particularly for a person with PMLD. However, subjective evaluations, such as those included in the psychological indicators, are likely to be the most valid (Chowdhury & Benson, 2011) yet, within the case studies, there is little evidence of these identified indicators being attended to (Findings 4.3.4, 4.4.3).

The aspiration to a 'good life' has gradually evolved with our understanding of the notion largely based on a sense of reason that runs, within Western culture, from Ancient Greece to the Enlightenment. This engendered the attitude that a good life

depends on being able to make good choices about life. As people with learning difficulties were deemed to have a deficient sense of reasoning, they were denied the opportunities to make such choices. It was not until the work of Sigmund Freud that the impact of emotions and the inner self were considered (Johnson & Walmsley, 2010).

A good life is more than a matter of choice: it relates to notions of the value of the person, the inner thoughts and feelings of each person. The thoughts and feelings of an individual about their experiences contribute to that person's sense of identity, irrespective of their cognitive ability (Weldon, 1986). Emotions and passions inform emotional intelligence independent of reason (Johnson & Walmsley, 2010). These notions challenge current thinking about learning disability and the ability of those with learning disabilities to have legitimate influence and ownership over their own lives. If it is considered that people with PMLD have the same right to a good life as others, they should be considered for their capabilities, not their deficiencies. People with PMLD would, then, have their capabilities recognised and appropriate resources would be available to enable them to function. They would be able to make choices and lead a life based on their own decisions and the acceptance of their emotional intelligence and inner lives, not just observable exterior activities.

If young people with PMLD are to be accepted as people with the potential to share a common life, to participate, to offer reciprocity, those around them may need to make more effort to respect and support them (Vorhaus, 2017). Each human being is unique; young people with PMLD are particularly so because of the individual complex difficulties that they experience. If this uniqueness is recognised, alongside the qualities that it brings to the diversity of the community, everyone may have the opportunity to benefit interdependently (Vorhaus, 2017) because we need our fellow human beings in order to share participation. People with PMLD are usually the recipients of care and protection and this has the potential to make others feel virtuous. A good life involves having opportunities to contribute to the welfare of others, to connect with the immediate community and that at large. These opportunities are denied to people with PMLD because it is assumed that this aspect of a good life does not apply to them. Young people with PMLD create a space around them, often due to the complexity of their difficulties, and this space challenges those around them to think differently to find

alternate ways of interacting. This challenge can also be viewed as a reciprocal achievement as it enhances the thinking of those around people with PMLD (Mercieca, 2013) and challenges the status quo regarding how young people with PMLD are perceived.

The transition for a young person with PMLD sits within many pre-existing structures with legal requirements, as laid out in the SEN Code of Practice and the impact of influential models of disability. The definition of terms can change over time and in different contexts. The Ancient Greeks considered baldness to be a disability because it detracted from the physically beautiful appearance to which they all aspired (Penrose). More recently, influential medical and social models of disability have emerged. Funding and support sources often change at the time of transition as young people pass out of children's social care and health services (Kaehne & Beyer, 2009).

At the heart of the transition structures and procedures set out in the legislation is the future life of a young person. The extent of the difficulties and complexities experienced by young people with PMLD can be seen in the description of the three young people in the case studies and can overshadow a young person's aspirations and inner self. This was particularly evident in the planning for Katy, where attention focussed on the support she will need and the health provision she will require. Overlooking the thoughts and the feelings of the young person can deny them access to facilities and opportunities that should rightfully be theirs as set out inequalities legislation (Equalities Act, 2010).

5.5. Health

In 1948, the WHO described health as a state of complete physical, mental and social well-being, not merely an absence of disease or infirmity. This definition of health was modified in 1984 to become the extent to which an individual or group can realise aspirations and satisfy needs to learn to change or cope with their environment. Within this definition, it could be argued that young people with PMLD all experience various forms of chronic health issues. The focus of attention on the health issues of this group of young people has influenced how they have been perceived by society at large. The impact on the young people's education is discussed in Section 5.3 above. Much of the

developments in educational opportunity are based on the gradual decline in influence of the medical model of disability and the evolution of the social model of disability.

The definition of PMLD includes the acknowledgement of significant complex healthcare needs (Ware 2004). It is important to acknowledge the influence of these healthcare needs but equally important that they do not define the young person and the potential development of their inherent abilities. The health needs of Jonathan Bryan could easily have been defined by his complex, severe healthcare needs, but he has been able to live a full life and contribute to society, while recognising the impact of his healthcare needs (Bryan, 2017). Odyssey, with sensitive support, has been able to overcome her fear of accessing health support to mitigate the impact of her healthcare needs (Lyle, 2016).

The attitudes of those around the young people with PMLD vary. Harry's mother recognised the significance of his health issues and the need to address them, adopting a matter-of-fact attitude. Harry's teacher had a similar attitude, while the TAs viewed Harry's health issues with concern and felt very protective towards him (Findings 4.2.3). The TAs working with Katy acknowledged her seizures but seemed to want her to get over them quickly and to remain her usual, jolly self. They did not seem to acknowledge the impact of the seizures on Katy and her need for quiet reflection following them (Findings 4.2.3, 4.4.4).

Whatever the attitudes of those involved with the young people, it must be acknowledged that their health issues had a significant impact on their lives. Harry and Katy required surgery, leading to an absence from school and non-engagement in social activities. Both experienced considerable pain and discomfort before and following surgery. The effect of chronic health conditions also had a persistent impact. Harry had nocturnal seizures, resulting in extreme tiredness from the nocturnal cerebral activity (Findings 4.2.3, 4.4.4). All the young people in the case studies were dependent on health professionals to provide resources to mitigate the impact of their health issues, including standing frames, hoists, wheelchairs, splints, communication aids, and access to health professionals.

The health issues that have been considered are physical; there is little evidence of attention to mental health issues, although some of the behaviours displayed by the young people could be interpreted as the manifestation of mental health issues. Harry's refusal of contact by repeatedly hanging his head could be an indication of depression, particularly when at school. His self-stimulatory activity could be a manifestation of a feeling of isolation (Findings 4.2.3). Linda's mother related that she was often tearful for no easily identifiable reason (Findings 4.3.2). The school noted that Katy could often become upset around food and at lunchtime, which could be a manifestation of anxiety attached to food and mealtimes (Findings 4.4.4). It has been found that mental health issues are more common in people with learning difficulties than in the general population and it is slowly being acknowledged that more needs to be done to develop provision in this area of need (Guidance for Commissioners of Mental Health Services for People with Learning Difficulties, 2013).

5.6 Impact of Others

The impact of others upon the lives of young people with PMLD is set within the context of the changing definition of this group of young people over time (see Literature Review 2.4). Education methods have developed and influenced how young people with PMLD are taught in schools (Watson & Simmons, 2014). Young people are subject to these influences; it is not their impairments but the response of people to their impairments that constitutes the problem (Kittay, 2019). How others respond to young people with PMLD can shape their development and responses to the world around them (Coupe O'Kane, 1998, Ware, 1996). Intensive Interaction builds upon this recognition by building trusting communication relationships between young people with PMLD and a communication partner (see Literature Review 2.6).

The impact that others have upon young people with PMLD sits within larger societal structures that direct and influence the way people behave towards this group of young people. Within the education system, targets and outcomes are written for them and future aims are decided. The case studies showed no evidence that the young people were included in identifying targets, outcomes and aims (Findings 4.3.3). In terms of the transition planning process, the data confirmed that Katy did not attend her meeting, while Linda attended but made no contribution. In both cases, decisions were made on

their behalf which had a significant impact on their future lives. These circumstances are reflected in the literature (see 2.7).

The attitudes and implications within the systems reflect the underlying attitudes of broader society, seen in Linda's mother's comment that many people wanted to protect Linda. She also commented that, at home, they pre-empted any potential difficult behaviour as did the staff at school (Findings 4.3.1), possibly in a manifestation of the medical model of disability which attempts to modify and protect the disabled person (see 2.4). The effect of these behaviours can send subtle, coercive messages to Linda and other young people with PMLD. The contribution of others can mean that their feelings of frustration are constantly diverted rather than acknowledged, that they are protected from situations that may cause them distress. Although these attitudes may be well-intended, they deny the young person the power of individual expression. There is evidence of a need in those who work with young people with PMLD to ensure that the young person is happy most of the time, although this may not be true for the vast majority of the population. To feel discomfort or the need for quiet reflection is a human experience, yet this can be denied to young people with PMLD, as seen in the TA's comment that the staff would cheer Katy up when she returned to the classroom. This was following a seizure after which, during the interactive session, Katy clearly demonstrated that she wanted to share quiet, thoughtful time (Findings 4.4.1). The situation just described is an indication of the young person not being effectively listened to.

The effect of this is that young people with PMLD can become passive because they realise that they do not have the agency to exert an influence. This attitude in those around them has a considerable impact upon the way the young people view themselves, as seen in the bewilderment of the young people in the Intensive Interaction sessions when they were not directed, but time was taken for them to initiate activity (Findings 4.2.1, 4.3.1 and 4.4.1). The impact of an interactive partner who endorses meaning for activity initiated by the young person has a creative and developmental impact for that young person and their relationship with the partner. This was evident in Katy's delight in the bead-throwing game that she initiated

(Findings 4.4.1). Within this game, a relationship of inter-dependency developed between the interactive partners.

Currently, many young people with PMLD are invisible to the general public. Only those who work with or who are family members of people with PMLD come to know this group of young people and this creates an atmosphere of apprehension around them, even in the schools they attend. A member of staff in one of the schools said that she felt very insecure when working with young people with PMLD (Findings 4.3.5). This feeling of insecurity must be communicated to the young people by other people's reactions. It is important that people who spend time with young people with PMLD feel confident and that they are in a relationship of inter-dependency with that young person (Literature Review 2.4).

5.7 Things That Are Difficult to Understand

Much of the behaviour and communication of young people with PMLD can be difficult to understand. The behaviour has meaning for the young person, but it is difficult for others to interpret. While those who know them well can attempt to interpret their communicative behaviour (Lacey & Ouvry, 1998), such interpretation can easily be biased. All the case studies showed examples of this effect. The research assistant interpreted Linda's leaning towards as an indication that she knew I was copying her (Findings 4.3.2). Likewise, the research assistant recorded that Katy was listening for the beads, another interpretation of behaviour (Findings 4.4.1). In my reflective journal, I note that I must not put my interpretations on Katy's behaviour of blowing raspberries and making kissing noises. I was aware of the temptation to impose interpretations rather than simply acknowledge the communicative behaviour (Findings 4.4.1). This conflict is demonstrated in the dual analysis of the interactive data for Harry. The data are analysed through the researcher lens and then through the supposed lens of Harry's views in an attempt to empathise with and reveal Harry's perspectives. The researcher analysis identified attributes that were within my frame of reference, such as mutual contact, and may have reflected elements of the interaction that I wanted to see, such as showing emotion. When attempting to analyse the data from Harry's perspective, there is an increased tendency to see the meaning of the behaviour for Harry, such as wanting to attract attention or share something (Findings

4.2.1). This is a subtle but important difference in interpretation. In many instances, other people are looking at the communicative behaviour of young people with PMLD, searching for meaning within their own frame of reference and it is this that makes the behaviour difficult to understand. When seen through the young person's eyes, it may have clearer meaning.

Some people readily acknowledged that they found it hard to understand the meaning of the young people's communicative behaviour. The TA who worked with Harry said that she found it hard to understand the meaning of his giggling when she took him to attend to his personal care (Findings 4.2.1). Linda's mother found it hard to understand why Linda became tearful, apparently for no explicit reason (Findings 4.3.2). When the young person's communicative behaviour is difficult to understand, this can create a feeling of rejection and lack of confidence in others. I noted this myself in my journal, recording that I felt a sense of rejection (Findings 4.4.1). It is possible that this negative effect of some communicative behaviour can lead people to put a positive interpretation on the behaviour to make the recipient feel better and more secure in themselves.

During the interactive sessions, Linda displayed communicative behaviour that was difficult to understand (Findings 4.3.2). The behaviour did not appear to have any communicative function between Linda and others; indeed, behaviours such as rocking with increasing intensity and rubbing her hands and legs with increasing intensity seemed to be sensory-based activities in which Linda was communicating with herself. Young people with PMLD are often difficult and unrewarding for others to communicate with and, as a result, people often give up communicating with them (Ware, 1996). This, in turn, causes young people like Linda to begin to communicate with themselves, which is what Linda may be doing in the case study. The essence of communication is that it should be developed and understood as part of an interaction with other people (Goldbart & Coupe O'Kane, 1988).

5.8 Thoughtfulness

Thoughtfulness emerged as a significant theme during the interactive sessions. The depth of thought revealed was an element that I had not considered. From my experience of working in schools, and other forms of contact with young people with

PMLD, it is an aspect of the young person's life that can easily be overlooked. Within the interactive sessions, when the young people felt confident and in control, they were able to reveal and communicate deeper aspects of themselves. They had the confidence to begin to reveal their perceptions of and responses to their surroundings rather than having the thoughts of others imposed upon them. This challenges those surrounding the young person to understand and appreciate what they have revealed and resonates with work on the relationship between thought and communication, between internal and external communication (Merleau Ponty, 1962). Katy demonstrated this confidence when she deliberately stopped and thought before she developed the bead-throwing game by throwing the beads in the opposite direction to where I was sitting and laughing as she did so (Findings 4.4.1). This thoughtful activity by Katy demonstrates a sense of agency in acting upon her surroundings rather than simply responding to them. The development of such agency requires discernment and thoughtful understanding.

The young people in the case studies took time out from interaction within the sessions by hanging their heads down (Findings 4.4.6, 4.2.1). This created a space for thoughtfulness that challenged me to quietly reflect upon the relationship between myself and the young person, to really concentrate upon the young person. The silence that can be experienced at such times creates space in a relationship for a reflective period that can otherwise be crowded out in the busy lives and relationships in daily life (Mercieca, 2013). The experience of Intensive Interaction can facilitate a sharing of experience and deeper knowing between the participants that are of great benefit to both parties (Berry et al., 2010; Kittay, 2019). This quality was recognised in my reflective journal when I noted that, through mutual engagement, Katy and I had a deeper relationship (Findings 4.4.6).

Reactions to young people with PMLD can be influenced by stereotypes (Dee, 2002), including those of low expectations, helplessness and dependency, which lead others to fail to look for meaning in their behaviour, particularly their thoughtful behaviour. Such a reaction can be perceived in the attitude of the TA who wanted to get Katy back into the classroom where she would appear happier rather than respecting the quiet thoughtful time Katy had experienced in the interactive session following her seizure (Findings 4.4.6).

Young people with PMLD are part of the wider community and have a contribution to make to that community, partly by – during periods of quiet thoughtfulness – challenging members of the wider community to engage in quiet reflection during which they may see things differently (Mercieca, 2013; Vorhaus, 2018).

5.9 Emotion

The impact of emotion is revealed throughout the data, both the emotions of the young people and the emotions of those around them. There is a need for emotional honesty with young people with PMLD. It is important to recognise emotions within people who work with and are close to these young people, perhaps to admit the sadness that they may feel because of the severity of the young people's disabilities. This is part of the relationship (Berry et al., 2012) and may explain why people are very protective of and want to care for young people with PMLD (Findings 4.2.3, 4.3.1). Leading on from this, there appears a strong sense that those people close to them want the young person to be happy most of the time. This can have the effect of denying the young person opportunities to display the whole range of human emotions experienced by others. Positive emotions, such as smiling and laughing, are affirming to the people in their company while negative emotions, such as withdrawal or anger, are much more challenging for others to acknowledge and address.

Behaviourist approaches can have the effect of concentrating on observable, extrinsic behaviours. The cognitivist approach addresses what is happening behind the behaviour (Simmons & Watson, 2014) and it is this approach that attends to the emotional hinterland of the young person. This hinterland can be very difficult to reach in a young person with PMLD (Kellett, 2003). Intensive Interaction provides a vehicle to establish relationships of equality where young people with PMLD can express and reveal their emotions in a relationship of mutual trust and empathy; its positive impact on the emotional well-being of young people with PMLD has been recognised (Nind, 2009).

The data revealed that the young people in the case studies had difficulty in expressing their emotions, and those close to them had difficulty in understanding and dealing with

those emotions. Linda and Harry both displayed self-stimulatory behaviour through which they may have been trying to express emotions. Linda's parents described her tearfulness, which they were unable to explain (Findings 4.2.1, 4.3.1). Often, the outlet for their emotion was diverted, for example when Linda presented with challenging behaviour (Finding 4.3.1). This confused expression and acceptance of emotion in young people with PMLD can lead to mental health issues that are largely unacknowledged (Guidance for Commissioners of Mental Health Services for People with Learning Difficulties, 2013).

5.10 Empowerment

My research question asks how young people with PMLD can be empowered to influence their own post-school transition process. Through the application of the principles of Intensive Interaction in this project, the young people have been empowered to take control of interactive exchanges. In the early sessions, each young person was bewildered and unsure how to respond when given control and expected to lead the interaction (see Findings 4.2.1, 4.3.1 and 4.4.1). As the interactive sessions developed, each young person demonstrated increased self-confidence and aspects of empowerment. Harry began to smile and share (Findings 4.2.1); Katy began to take the lead in activities (Findings 4.4.1); Linda had sufficient confidence to persevere with her communication aid until she communicated what she wanted (Findings 4.3.1). The interactive sessions allowed the young people to interact in a way that was meaningful to them, offering them empowerment (Vorhaus, 2017). Providing the opportunity for the young person to be known and to know another person demonstrated value for that young person. By feeling this value, the young person felt empowered (Kittay, 2019). The interactive sessions were conducted in such a way to provide opportunities for each young person to have agency and influence the behaviour of someone else. This also provided experience of empowerment (Mercieca, 2013). One aspect of empowerment is to understand from the young person's point of view, such as when Odyssey's fear was understood, empowering her to overcome it and be able to visit the dentist (Lyle, 2016). This aspect of empowerment is reflected in the work of Sen (2017) who believes that empowered young people are then able to take advantage of the resources available to them.

In different environments, the young people displayed different aspects of empowerment: Harry seemed more in control in his home environment as a result of his mother's attitude (Findings 4.2.5). Often, it is the attitudes of others, including the desire to protect, that inhibit the potential empowerment of young people with PMLD.

Throughout the research report, examples have been found where young people with PMLD can experience being empowered. These examples will be developed in Chapter Six – Conclusion.

CHAPTER SIX

CONCLUSION

6.1 Introduction

As noted in the Introduction to Chapter Five, the project emerged from my desire to understand and develop the contribution that young people with PMLD can make to their post-school planning process, and developed from my observations as a practitioner in special education. In my role as a headteacher, in particular, I was aware that young people with PMLD did not have access to appropriate resources to enable them to influence their post-school planning. Based on this observation and with skills acquired as a headteacher, I embarked upon this research project.

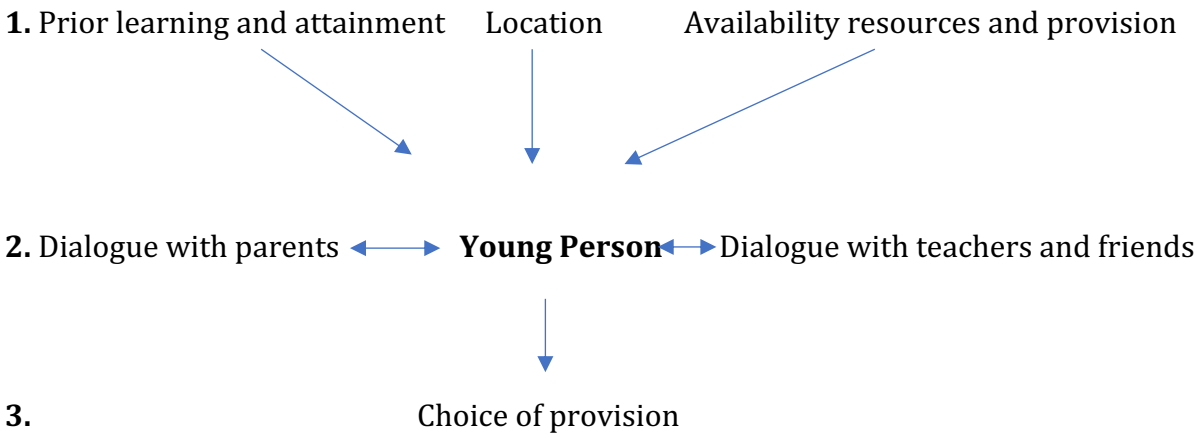
I conducted an exploratory Pilot Study (see Methodology 3.2), applying techniques of observation and interviews with school staff and parents that I had used in my work as headteacher. Following the review and analysis of the Pilot Study data, it became apparent that the methods used in the pilot were not fit for the purpose of the main research project (Methodology 3.1). These methods did not enable me to have direct communication with the young person; I had no opportunity to get to know the young person as an independent individual. This realisation was a critical moment in my research journey. I realised I had to search through my experience as a headteacher to identify a method through which I could directly communicate with each young person, getting to know them. I acknowledged that the problem lies with the inadequate research tools available to work with these young people, (Nind, 2014).

I identified Intensive Interaction (see Literature Review 2.6, Methodology 3.1) as a potential communication method. I had used it in school but not as a research tool so this use of Intensive Interaction as a research tool was innovative. I knew that it would take time to listen and get to know these young people with PMLD. The core research is based on one-to-one interactive sessions with each young person in the case studies. The aim of giving the young people a voice was also reflected within the research methodology; in this sense, the subject and the object of the research developed in tandem in a reflexive manner (Kamler & Thomson, 2014). Other, supplementary methods were employed. During the pilot, it became clear that semi-structured

interviews, although useful, did not allow people to share their personal thoughts about their relationships with the young people. In the main project, semi-structured interviews were modified to become simple dialogues. This fitted well with the ethos of the project which emanated from the egalitarian approach of Intensive Interaction. Throughout the pilot study, I kept a journal that became more reflective as the pilot developed, revealing my journey as a researcher and generating valuable data. As part of the main project, my reflective journal was an identified element of the research methodology. Finally, it was important to collect and analyse documentary data relating to each young person's transition journey.

From the interactive sessions, subsidiary influences emerged as highlighted in Chapter Five – Discussion. The contextual issues have a significant influence on the lives of young people with PMLD and are an important part of the research outcomes. Before considering the key findings of the project, I reflected on the mainstream model for young people to select the post-16 provision of their choice. This is shown in Figure 6.1.

Figure 6.1 Mainstream Student Post-16 Selection Process



The Findings revealed that lines 1 and 3 in Figure 6.1 were the same for young people in mainstream education and those with PMLD. The differences occurred in the dialogues shown in line 2.

As discussed in the introduction to Chapter Three – Methodology, the research question emerged from my own feeling of dissatisfaction regarding the participation of young people with PMLD in the transition planning process.

Research question

How can young people with PMLD influence their own post-school transition planning process?

6.2 Key Findings

I started my research hoping to be able to identify ways in which young people with PMLD could be included in their post-school planning within the existing system. As the project developed, it became clear that many aspects of the existing system are not fit for purpose for young people with PMLD if these young people are expected to make a significant contribution to their planning. This is because young people with PMLD do not have the opportunity to engage in the dialogues identified in line 2 of Figure 6.1 for reasons revealed by this research project. At the heart of the research are the interactive sessions; these are supported by analysis of the documentary evidence associated with the transition process.

6.2.1 Intensive Interaction

Throughout the interactive sessions, the young people revealed aspects of themselves which, on many occasions, were subsequently endorsed by other people who knew them well. Linda's mother, after observing an interactive session, commented that she had seen Linda behave in that way with one other person and often applied an interactive approach with Linda (Findings 4.3.1). The young people developed self-confidence and the ability to participate, lead and enjoy interaction with another person through the interactive sessions (see Findings 4.2.1, 4.3.1, 4.4.1). The Intensive Interaction sessions revealed aspects of the young people's inner world and their ability, in a close relationship, to have a profound impact upon another person (ref Findings 4.4.1). The case studies have demonstrated that young people with PMLD are thoughtful and reflective if allowed to express this aspect of themselves and, therefore, that young people with PMLD can potentially contribute meaningfully to their post-school transition planning if the appropriate strategies for communication are in place.

6.2.2 Young People with PMLD – Preparation for Transition Planning

The demonstration of choice is an important part of participation in transition planning. There are examples of choice being included within the young people's learning at school (ref. Findings 4.2.1, 4.3.3). These activities are not identified as preparation for choices at the time of transition; they are often very simple structured choices. The Intensive Interaction sessions revealed that the young people made very definite choices regarding what they wanted to engage with and what they did not. To demonstrate choice is an essential part of communication. Throughout the Intensive Interaction sessions, the young people communicated choices including what they chose to communicate to the partner. They also demonstrated that they could communicate at many levels from a superficial level of engagement with a given activity, to a deeper level of communicating feeling or that they themselves were reflecting.

Many of the educational achievements recorded in annual review reports refer to functional aspects of learning, specific subjects or life skills. They do not relate to preparation for future choices and developments. Community involvement was identified through the transition planning documentation as important for young people with PMLD. There was little evidence that the young people in the case studies were receiving an education that would prepare them to contribute to their communities (Findings 4.2.2, 4.3.3). Opportunities for them to contribute were not recorded or evident in the transition planning documentation (Findings 4.3.4, 4.4.3).

How government legislation relating to transition is communicated to those responsible for implementing it and how these people interpret it at a practical level emerged as an issue. In the present system, the young person is represented in the planning process by various significant people who provide information.

The three young people who were the subjects of the case studies did not contribute to their post-school transition planning. Neither Harry nor Katy were present at their respective meetings, and Linda was present but did not contribute (see Findings 4.3.4).

6.2.3 Impact of Professionals

The professionals working with young people with PMLD have a significant impact upon the communication of each young person but also a much wider impact. The emergence of these issues throughout the data collection and analysis added breadth to the theme of communication.

For example, one TA was responsible for all the transition visits to college with Linda. She accompanied Linda on each visit and conveyed much of the vital day-to-day information about Linda's care and support requirements. However, she displayed little confidence in her role, seeing herself as 'only the TA', with the teachers in control of the transition. It appeared that she saw herself as a messenger and did not expect to influence the transition process despite being the carrier of vital information regarding the young person. Had the TA been more confident in her role, she may have been more assertive in the manner in which she conveyed important information to college staff (see Findings 4.3.4).

The transition review meetings revealed the impact of other people on the lives of the three young people in the case studies. Others had decided whether or not they should attend. It is not clear from the documentary evidence who decided that two of the young people should not attend. It may be assumed that the decision followed custom and practice within the given institution, supported by other significant people included in the process. These are people who have considerable power within the process: headteachers, teachers, social workers and, in some cases, parents. While Linda attended her meeting, at no point did she contribute. Throughout the meeting, other people contributed on her behalf (4.3.4). The fact that nobody in the meeting challenged the fact that she was not contributing supports the assumption that it was custom and practice in this institution that young people with PMLD did not contribute to their own planning meetings.

Judgements and comments about the young person's progress are made and recorded in school reports. These judgements are not discussed with the young person, as they would be in a mainstream school. At the point of planning future placements, these judgements and comments on reports are influential, as shown in Figure 6.1.

Throughout the research process, I was aware that I was making judgements that were having an impact on young people. This was evident when I commented in my journal that it had been a good session (see Findings 4.3.5). At no point did I consult the young person for their views about the session. Throughout the sessions, the young people demonstrated their ability to resist the impact of others by hanging their head and refusing to communicate. This was also evident in other situations, as reported by staff.

6.2.4 Parents and Professionals

The case studies revealed that the communication between parents and professionals was variable. When considering the impact of professionals on families, it must be remembered that the parents of young people with PMLD have to maintain relationships with a wide variety of professionals, all of whom have some influence on the transition process. For the purposes of this project, the emphasis was on school staff. The teachers in all three case studies felt they maintained a close relationship with parents. There was some evidence that approaches taken at school were helpful in the home situation, for example, the management of Linda's behaviour (see Findings 4.3.2). Other examples showed that information from home could have been more influential at school, for example, the activities that Harry enjoyed at home (see Findings 4.2.2). The impact of these relationships fed into the transition planning process.

The transition to post-school provision for a young person with PMLD is a very anxious time for families (Strnadova & Evans, 2013), as seen in Linda's case study when her mother expressed her relief that Linda's first week at college had passed without a problem (see Findings 4.3.3.4). At the time of transition, young people and their families are leaving the support of school staff whom they may have known and trusted for up to fifteen years. It is also a time of transition to adult services in health and social care. Young people and families are coping with a complete change in the support for their vulnerable young person with PMLD.

Within the transition process, the role of parents can vary depending on the attitude of individual parents. For example, Katy's parents were very forceful in stating what they wanted for their daughter, while Linda's appeared to be more passive and accepting (see Findings 4.3.4, 4.4.3). This variable approach affects attitudes towards the young

person's aspirations. The understanding of relationships within the transition process can be seen as a struggle for power. In Katy's case, everyone apart from her parents thought she should go on to attend a college provision but her parents wanted to assure her safety and continuity of provision and so she went to a very sheltered specialist provision. Despite the struggle between Katy's parents and other professionals, Katy's own views were not considered.

Parents feel vulnerable at the time of transition: their child is vulnerable and in need of particular understanding and they are worried that their child will not have the specific support and understanding which they need in a new situation. They feel anxious about how their child will cope with the new, unfamiliar situation and are, at this point, dependent on the professionals who effectively control the access to future provision. The parents want their child to have on-going provision and are aware that these opportunities are limited. In this situation, the parents feel anxious; they know their child but feel powerless to influence decisions. Although superficially they have been consulted, they may not have been truly listened to and enabled to influence decisions.

Despite the potential anxiety within families at the time of transition, home and family can provide a point of continuity and support for the young person. Following my visit to see Linda at college and my subsequent feedback to her parents, it became apparent that they had considerable knowledge and understanding of Linda that was not recognised by the college. They knew what had gone before in Linda's life. Home was a constant place of belonging for Linda, a repository of knowledge and relationships (Nind & Strnadova, 2020).

6.2.5 Health Issues

There was evidence that health issues, particularly physical health issues, had an impact upon young people. Health issues relating to young people with PMLD can be broadly seen in two categories: ongoing chronic health problems and shorter-term acute problems. The latter can be the consequence of remedial surgery or the sudden deterioration of chronic issues. The chronic issues become a matter of ongoing management and adaption of the young person's activities while the acute problems impact upon attendance at school and other involvements (see Findings 4.2.2, 4.2.3).

These problems can also affect transition plans: Katy was admitted to hospital in December before she was due to leave school, as a result of a deterioration of a chronic condition, her epileptic seizures. She was not fit to return to school until mid-February and this posed many challenges for her transition planning and increased her parents' anxiety at this critical point in her life. This example is typical of the unpredictability of the health issues with which young people with PMLD have to live.

The case studies showed no explicit awareness of mental health issues for young people with PMLD, despite examples of behaviour that, in other people, could be interpreted as indicators of mental health problems.

6.3 The Value of the Research Project

The project is unusual because it puts young people with PMLD at the heart of the project. Many studies have been conducted with young people with various SEN issues but, due to the complexities they face, young people with PMLD rarely take centre stage in a research project. In this project, they remained centre stage throughout.

This project was identified as a consequence of observations made while I was a headteacher; in this respect, it is practitioner-led and emerges from current practice. There is particular value in a stance firmly based in practice, rather than a phenomenon identified by a researcher remote from the reality of the issues. I brought to the project substantial experience in the field of special education and working with young people with PMLD in particular, yet as a researcher I was a novice. This juxtaposition provided a clarity of perspective. As a researcher, I became the outside observer of a situation with which I was very familiar as a practitioner; I looked with new eyes at what I had previously seen as custom and practice (see Methodology 3.2).

Throughout the pilot study, I kept a journal, initially as a general journal and, later, as a personal reflective journal. In the main project, the journal developed further, recording my thoughts and feelings about the interaction with the young people and others involved in the project. Through these reflections, a different perspective emerged on attitudes and practices that were assumed custom and practice. The particular value of this element of the study is how it highlighted the ongoing need for people who work

with young people with PMLD to step outside their existing practice and constantly review their attitudes and practice.

The research uses methods accessible within the school environment. In particular, Intensive Interaction is used in many schools and could be adapted as it has been in this project. The project emerged from practice and has aspects that can be applied within current practice. It was conducted by an experienced practitioner who is very familiar with young people with PMLD, which gives it added credibility. The current system of post-school transition planning was scrutinised through the lens of a retired practitioner, providing in-depth knowledge of the system while maintaining distance from it. This offered a different perspective of the system, the young people with PMLD and the relationship between the two. The use of Intensive Interaction to get to know a young person with PMLD on their own terms not only has the potential to provide a voice for the young people in the transition process but also offers opportunities to contribute to the research process. Exploration of this dual benefit adds further value to this project.

6.4 Relevance of The Project

The project is rooted in practice: the research focus was identified as a problem in practice. It addresses two problems associated with young people with PMLD, concerning how young people with PMLD can meaningfully contribute to transition planning and the research process. The outcomes of this project identify that the very issue to which the young people are expected to contribute is inaccessible to them. As an analogy, when my friend, who is a wheelchair user, travels by train to London, the train facilities are sometimes such that she has to sit virtually in the corridor. On other occasions, she can access a compartment where she can sit in her wheelchair and travel alongside other travellers. When in the corridor, she is being accommodated within a transport system that claims to be accessible to disabled people but offers minimal provision. In the purpose-built compartment, she and her disabilities are accepted and understood and she is fully accommodated. The transition planning process states that young people should have a voice, yet they are metaphorically left in the corridor as observers. With the insights and deep understanding achieved through the interactive sessions, it is possible, if the system is altered, for young people to be accommodated

and contribute, just as my friend in the purpose-built compartment was accommodated on the train.

The outcomes challenge the existing assumption that young people with PMLD should fit within the system despite the apparent lack of thought given as to how they can be part of the transition planning process. It is reminiscent of the introduction of the National Curriculum when all pupils were expected to follow the same programmes of study. On one level, the inclusion of pupils with PMLD in the National Curriculum was positive, as it extended the range of their curriculum, but virtually no consideration was given as to how the curriculum might need to be modified to allow them to meaningfully access it. Eventually, the need for change drove developments in planning an inclusive curriculum, so that pupils with PMLD could be more meaningfully included in the National Curriculum.

Similarly, the current system needs to be modified to enable young people with PMLD to contribute. For young people to have influence in their post-school transition planning, organisational change is required at all levels. It was evident in this project that, at the macro level, the transition planning process and administrative requirements (such as standard forms to be completed) did not reflect the needs, capabilities or aspirations of young people with PMLD (see Findings 4.3.4, 4.4.3). At the meso-, or intermediary, level of school leadership, there was evidence that the school was attempting to accommodate the national administrative requirements and forms to be filled, but were doing so indiscriminately, with little attention to the particular needs of each young person with PMLD. At a micro classroom level, it seemed that many opportunities for meaningful input into the transition process were missed both by staff in the classroom and the young people themselves. The valuable observations that have arisen from the project have considerable relevance because they clearly identify those systems currently used in the schools in the case studies. As a result, the areas requiring future change can be clearly identified and proposals to effect this change formulated. These will be discussed in more detail in subsequent sections of this chapter.

The project sits within a cultural ethos and attitudes; it develops an understanding of where young people with PMLD sit within this climate and why it prevails (see

Literature Review 2.7). There is a common theme of access for young people with PMLD, as demonstrated by the limited response within the documentary evidence regarding the young people's participation in a wide variety of activities and the need for appropriate modifications to enable access. This project forms part of a wider need for young people with PMLD to have meaningful access to be able to participate in and contribute to a wide variety of activities at school and in the wider community. The increased understanding of the issues arising from the outcomes of this project will contribute to solutions in this wider need for change.

6.5 Implications of the Project

It must be acknowledged that the current project represents a small sample of young people with PMLD in two schools within the same county. Nevertheless, it raises issues that may be common to other young people with PMLD throughout the United Kingdom. The implications of the project challenge existing policy and practice for young people with PMLD. As stated in the previous section, these implications exist at a macro-governmental level, both at a meso-school leadership level and at the micro-classroom/individual level.

At a macro governmental level, there are implications for policy and practice. The rhetoric of the policy that all young people should be included in their own post-school transition is admirable and aspirational. The keyword here is aspirational: policy may be aspirational but, if it is not implemented for a wide variety of reasons, it raises issues relating to governmental practice. As has been demonstrated in the documentary evidence for the case studies, despite aspirational policy these young people were not included in their post-school transition planning. The forms associated with the planning need to be completed as a statutory requirement but their design and the questions asked are not appropriate for young people with PMLD. It would seem that government practice does not include the facility for feedback regarding the suitability of the forms. This has implications for future government practice regarding the suitability and implementation of policy (see Literature Review 2.4., 2.7).

At a meso- level, the project has implications for school leaders. Headteachers have a certain amount of autonomy within their schools and can look critically at the transition

planning practice within their school. This has indeed occurred within one of the schools in the project, and changes are beginning to be made to the way that young people with PMLD are included in transition planning meetings. The headteacher and senior leaders set the tone, values and ethos of the school. This, in turn, influences attitudes and relationships within the school, as was evident in the two schools within this project: one was very protective towards its pupils, whereas the other school viewed care as important but did not allow it to inhibit the focus on pupil progress and autonomy (ref. Findings 4.2.4, 4.2.6, 4.3.3). The headteacher and senior leaders control resource allocation and staff development and these also have an impact on the transition process. Roles and responsibilities within the school are within the gift of the headteacher and senior leaders: they decide who attends transition planning meetings and the roles of people within those meetings. This can create a hierarchy within the planning process; for example, the TA who supported Linda on her college visits did not feel she had much authority, yet she had a great deal of relevant information.

Class teachers at a micro-level influence the young person through relationships within the classroom. In a special school, class teachers maintain close relationships with families and other professionals involved in the young person's life. At a time of transition, it is the class teacher who co-ordinates activities and communication between the various people involved. This project has implications for class teachers. In one school, the relationships amongst classroom staff were difficult (see Findings 4.2.6): colleagues did not have a shared approach to the young people and what would benefit them. In another school, the TA with a key role in the transition of students did not think her opinion was important. Attitudes such as these can affect the young person at the point of transition, particularly when they are very dependent upon the support and understanding of the staff working with them.

The project has highlighted the areas identified in 6.1 of this chapter, all of which have implications for future development. It is the middle section, the opportunity for dialogue with other people, that is currently missing for young people with PMLD and carries implications. Recognition of this flaw poses the question as to how young people with PMLD can be given this opportunity, to achieve parity of opportunity with their

peers. There is evidence within this project as to how this may be addressed in the future.

6.6 My Journey as a Researcher

My research journey began from feelings of dissatisfaction with the progress I had made as a headteacher to improve the inclusion of young people with PMLD in their post-school transition planning. As a consequence, I decided to investigate the situation further and put my initial thoughts into action. At the beginning of the research, I was a recently retired headteacher of a special school and current CEO of a local charity providing post-school provision for young people with PMLD. I began the research project with a practitioner focus, derived from my practitioner observations.

My previous experience had both negative and positive impacts upon my research. As stated above, the research grew from a personal sense of disappointment with what I had failed to address as a headteacher. This disappointment may have contributed to the lack of confidence I felt at the beginning of the research process. In the pilot, I applied methods that had been common practice in the school setting, with little thought about their appropriateness for this research project. Although I realised their limitations when I analysed the pilot data, this illustrates a potential blind spot brought to the research from my previous roles. As the research developed, I became aware of other blinkers I had developed from my previous experience: I had developed a narrow view of young people with PMLD, merely seeing the part of them that presented in school. This infiltrated my expectations of them and their inner abilities. Similarly, I had developed a fixed view of parents and their understanding of their child. All these aspects had developed over time and I had symbiotically absorbed them as part of the education culture.

The benefits from my previous experience must be acknowledged: my knowledge and understanding of this field of education enabled me to identify Intensive Interaction as a research tool that could provide young people with PMLD to contribute to their transition process. From my previous experience, I was able to place the research within a socio-political context. I was able to understand why practitioners could not challenge what was not working, simply due to the day-to-day demands of the job.

Through my previous experience, I was able to relate to the various participants with understanding, although the research process itself has increased the depth of this understanding.

Throughout the research project, my practitioner experience and focus were useful but, as the research developed, my focus altered. I began to see through the eyes of a researcher, using a lens of enquiry which led to deep and challenging reflections on former assumptions and accepted practice.

This juxtaposition became apparent when I was analysing the data from the pilot study. I had used practice derived from my school experience to inform how I would gather information about the young woman, the focus of the pilot study. The analysis revealed that I had asked other people about her and had observed her in various situations associated with the school. This was common practice in education when wanting to find out about a young person. At no time had I interacted with her to learn directly from her what was important to her (see Methodology 3.2). My practitioner knowledge was, however, useful in enabling me to identify Intensive Interaction as a potential means of getting to know the young person directly without the influence of other people. The interplay between my development as a researcher and the benefit of my practitioner experience has been a developmental theme throughout the project. As the research developed, I became increasingly aware of how accepting of the status quo I had become as a practitioner. While I was aware that government rhetoric for the transition process was not fit for purpose, I had become overwhelmed with other demands and did not challenge the transition processes for young people with PMLD. Throughout the research project, this close practitioner awareness of situations gave me empathy and a deeper understanding of situations which otherwise I may have found extremely frustrating, for example, when the Acting Head said I could not resume my work with Harry in the following term (see Methodology 3.2).

During the pilot study, I kept a journal, often recording my personal reactions to situations within the study. I developed this concept of a general journal into a specific reflective journal to record my personal thoughts and reactions to events in the research process of the main project. The journal provided many insights into my

journey as a researcher. It revealed aspects of the young people which, as a busy practitioner, I had taken for granted, and showed how I reacted to the young people differently as a practitioner and as a researcher. These insights were an important part of my research journey. The research process made me focus in detail on each young person. It provided an opportunity to sit alongside them and befriend them, to develop a relationship of mutual trust. Gradually, as the research developed, my attitudes and assumptions from my time as a headteacher were drawn into question. In the course of the interactive sessions, the young people revealed themselves to me in ways that I had not previously considered. I began to realise that I held subtle prejudices and low expectations that blinkered my approach to these young people (see Findings 4.2.6). From my teaching experience, I had brought into the research process the need to be constantly making progress. This was not helpful; I had to let it go and allow the young person take the lead. Although I believed this to be the correct approach, I still found it hard to do, making me realise how deeply entrenched these attitudes are within school cultures. My understanding and appreciation of the young people grew in depth and respect. I started the project believing that they should contribute to their post-school planning. My research journey revealed that my previous concept of this contribution was not fit for purpose; it had changed because of what the young people were showing me about themselves. I realised what a small part of the young people I had previously known, only occasionally getting a glimpse of their inner selves, their hidden depths as individual people.

The research process enabled me to have a different relationship with parents other than the one I had as a headteacher. I noted a particular aspect of this following one home visit to Harry's mother (see Findings 4.2.6). Through the research, I had glimpses of the anguish parents experience at times of transition (see 4.2.6, 4.3.2, 4.4.3). I came to understand their deep knowledge and love of their child, yet also their vulnerability: their child had multiple difficulties and they were trying to work within a system that they did not feel a part of, did not understand and felt powerless to influence. My perspective changed as I came to realise that the education system often gives insufficient respect to parents. Understandably, professionals within the field should have different views from parents but government legislation states that parents should

be listened to. Despite evidence that parents were listened to, my journey highlighted that they still felt very vulnerable within the system.

In the course of the research process, I have learned much about myself and the attitudes I had inadvertently adopted from my role within education. I began the research from what I thought at the time was a position of knowledge about young people with PMLD and the influences upon their lives. As my research developed, I had an increasing sense of humility and a realisation of how much I had not noticed in my various roles in education. My experience and knowledge from my previous roles were, however, useful in enabling me to identify methods for the research and my background enabled me to work with a certain degree of confidence and knowledge.

I realised as the research progressed that many surrounding issues affected young people's contribution to the transition process. The transition process sits within a socio-economic structure that has evolved over many years, influencing institutional and individual attitudes which, in turn, influence attitudes within the transition process. The research process has enabled me to stand back and see the transition process within a wider context. The research question has led me to identify alternative ways of approaching the lives of young people with PMLD, such as the work of Amartya Sen. In this respect, the research journey has opened new vistas of possibility and approaches for young people with PMLD.

Through deep reflection on the research process and tools, I have developed confidence. I began this journey feeling very apprehensive about approaching a difficult area with few tried and tested research tools. Within the academic community, I was trying to present research about young people who may be functioning at a very limited cognitive level. I found it challenging to articulate the level of difficulties that these young people experienced. They needed to be presented so that they had the respect they deserve and that the research was valued within the academic community for that, in turn, would give the young people a form of academic value.

As a researcher, I have learned a tremendous amount and gained new insights, particularly about the young people, their inner world and a deep knowing which I had

not previously considered. I have realised the value of in-depth study, particularly when used with vulnerable people to give them time to express themselves. I have become aware of the unique contribution that this group of young people can make if given the circumstances and opportunity to do so, and the system they inhabit. The further I have delved into the research question, the more complex the issues raised have become; one issue reveals so many others. The question remains as to how the research actually applies to practice: throughout the research process, it was evident that busy practitioners were reacting to immediate issues, with little time to respond to the deeper issues revealed in the research.

I have learned a lot about myself as an educational professional and a researcher, the interplay of these two roles and the need, as a researcher, to stand back and examine oneself with honesty and rigour, peeling away pre-conceptions. Only in doing so is the researcher able to identify and acknowledge alternative realities as they may appear to other people.

6.7. Things I Would Do Differently in Future Research

Researchers are advised to prepare meticulously for their project including, for example, conducting an extensive review of the literature to gain a clear perspective of the context of their research, the knowledge that has previously been established and areas of new knowledge that might yet be explored. A researcher can use such an approach to clarify and inform their stance in relation to their project before data collection begins.

In my case, reading a broader range of texts at the outset might have helped me to challenge my potential underlying prejudices and particular viewpoint at an earlier stage. It is possible that a more nuanced attention to the associated literature would have helped me to refine my research question with increased clarity and focus. However, my approach, while less conventional, had benefits: as the project evolved, I was able to maintain a responsive dialogue between the research and the literature and this interactive approach allowed me to follow up issues as they presented throughout the research process.

When I was developing the research methodology, I was uncertain whether Intensive Interaction would be an effective research tool to use with young people. In retrospect, I think I could have been more confident in this approach, given my use of it in other circumstances in schools. The interactive sessions are at the heart of the project and, therefore, I should have allowed more time with each young person; this would have enriched the quality, depth and range of the data collected. The data that was generated highlighted many issues but a broader range of data to draw upon was needed, as became evident during the analysis. As the research developed, I wanted to spend more interactive time with Linda after she had left school and arranged some interactive sessions with her at home. This proved to be beneficial to the project: it was helpful to have interactive sessions in different settings, particularly the home setting where the young person felt relaxed. It would have been useful to have given the other two young people this opportunity.

As the research evolved, it raised many subsidiary issues. I found these interesting and many linked to experiences from my professional career. I became distracted by these supplementary issues, for example, the relationships between the classroom staff (see Findings 4.2.6) which did have an impact on the classroom environment and made a peripheral contribution to the research question. At the point of data analysis, I decided which issues were central and relevant to the research question. The project is robust and stands up to reflective probing through the development of my reflective journal and thorough discussion with other professionals.

6.8 Limitations of The Project

The project is small scale and includes only three case studies from two schools within the same county in the United Kingdom. This places limitations upon the study, although the small number of cases has enabled the pursuit of a deep understanding of each young person. This deep knowing is essential when working with young people with PMLD because they face many barriers to communication and other activities. A great deal of time is required to allow the young people to show themselves and what is important to them. It could be seen as a limitation of the study that one of the young people had fewer profound difficulties. However, as discussed in Methodology 3.3,

where I explain the selection of people with PMLD for this study, I have adopted a broad definition of PMLD. I also note that PMLD can be seen as a spectrum of severity and that a person may be defined as having PMLD in one setting, yet, in another, the PMLD label would not be applied.

The methodology is exploratory; it has not been tried and tested in various situations. It applies a method of sharing time with young people with PMLD that is used in schools and some adult services. To my knowledge, it has not previously been used as a research tool. The aim of using Intensive Interaction was to facilitate the young people's ability to express themselves directly without the intervention of another person. While its lack of previous use in this context could be seen as a limitation, it is also an innovative aspect of the study.

The project has only scratched the surface of the problem: it has identified a method whereby young people with PMLD can express themselves and share things about themselves that are important to them. What they have revealed does not readily fit into the current transition planning process. The project addressed the research question and provided responses which can be followed up in subsequent work. The exploratory structure of the project has revealed aspects of the young people that are important to them. These have been expressed directly to the researcher without the interpretation of a third party and challenge how the current system meets the needs of young people with PMLD. The interpretation of the data has provided challenges. It should be acknowledged that any research project is subject to the interpretation of those conducting the research. However, content from young people with PMLD is even more dependent on interpretation. Evidently, the researcher's and research assistant's observations and reactions are their influenced by their interpretations of the young people in the case studies. This is a potential limitation of any research with young people with PMLD. The reality is that it is very challenging for this group of young people to express themselves authentically, and it is equally challenging for other people to create situations where these young people are truly listened to.

6.9 RECOMMENDATIONS

6.9.1 Introduction

The recommendations identified are specific to the transition process but have implications for many other areas of the young people's lives at a micro-level for practitioners, a meso- level for school leaders, and at the macro- level for policy-makers. The recommendations encompass preparation for participating in the transition process, organisational aspects around the process, roles and responsibilities within the process and wider policy implications.

School leaders have a pivotal role to play: they are in a position to influence practice in their school and possibly other schools through school leadership networks; they have opportunities to feedback to and influence policy-makers and they are in a position to see clearly what is happening on the ground, what needs to change in terms of practice and at a wider, policy-driven level. I identified the need for this research project when I was a school leader and it has developed from my practice as a school leader. Thus, the recommendations are written through the lens of a school leader, taking into consideration the factors relevant to implementing the recommendations at the levels of school practice and influencing policy-makers.

In implementing change at a school-based level, it is important to pay attention to the school ethos and values, as these underpin all activity within the school. This project recommends a school ethos that emphasises a commitment to the following:

- Personal autonomy and respect for each individual young person;
- The participation of each young person at all levels;
- An understanding of each young person from that young person's point of view.

The school ethos needs to be understood, accepted and adhered to by the whole community because it needs to underpin all activity within the school. For the purposes of the project recommendations, the ethos needs to be particularly apparent in aspects of transition preparation and implementation. It should be put into action through clear, whole-school aims that will contribute to the transition planning process. Emerging from the recommendations, the following aims are important:

- To develop each young person's idiosyncratic communication and decision-making skills;
- To fully prepare each young person for participation in their transition planning process;
- To view and note each young person's contribution to their class, school and wider community activity.

Each aim needs to be broken down into specific elements and actions, identifying the people responsible for implementing and monitoring the actions.

6.9.2 To Develop Each Individual Young Person's Idiosyncratic Communication and Decision-Making Skills

The understanding, acceptance and development of the young people's idiosyncratic communication by everyone involved in the preparation is an essential pre-requisite for their ability to influence their own transition planning process. A positive attitude towards their communication attempts is an important part of the preparation for the transition. Their communication needs to be acknowledged and valued in all aspects of their lives. A school leader is in a strong position to influence the development of the above-mentioned attitudes and attributes, providing opportunities for training and developing an understanding of idiosyncratic communication, appreciating that each young person has developed their own particular means of communication that works for them, and supporting staff to reach a shared understanding and commitment to enabling each young person to communicate in a way that has meaning for them. It will be necessary for staff to develop deep listening skills, giving attention to the whole person. Within this understanding will be an appreciation of the communicational value and meaning of what can be seen as challenging behaviour. Challenging behaviours can present in an extrovert manner or an introvert manner, such as that displayed by Harry (see Findings 4.2.1). Essentially, communication is a two-way process, with the response to the communication an important part of this mutual process. A positive response to the communication of a young person with PMLD validates the young person and encourages them to develop their communication.

Intensive Interaction (see Literature Review 2.6) provides an approach whereby the young person feels valued. They enter into a mutual, reciprocal communication partnership with another person. This encourages young people to have the confidence to reveal aspects of themselves that are important to them. To develop an interactive approach within a school, whole-school training would be needed and it would also be beneficial for parents to receive similar training. Designated members of staff would need to develop more in-depth skills to work with individual young people developing interactive relationships with deep understanding. These interactive sessions would provide information for and become an accepted tool in facilitating the young person's contribution to the transition planning process. Through the knowledge that the young person has been able to reveal about themselves, a visual personal statement can be prepared in collaboration with the young person.

Planning the transition into post-school provision requires the young person to make choices, an integral part of communication. In order for the young person to understand what a choice might entail – the implication and consequences of their choices – they need to experience making choices throughout the school curriculum. This requires a potential change in curriculum planning and delivery throughout the education of all young people with PMLD and needs to be implemented from at least the beginning of the secondary phase of education in Year 7. Choice needs to be an integral part of the curriculum. The choices that young people make must be adhered to, allowing them to experience the negative and positive consequences of their choices.

6.9.3 To Prepare each Young Person for Participation in their own Transition Planning Process

The preparation of young people to contribute to their transition process involves the commitment and shared understanding of all those involved in the process and those supporting the young person through this journey. This will enable the young person to feel confident and relaxed throughout the transition. To achieve this, a range of training and partnership development will be necessary, which should include parents, as they have a vital role to play in the transition and need to be acknowledged as equal

partners. All partners need to understand the transition process and acknowledge the different perspectives that the various people bring to the process.

There needs to be clarity about the purpose and expectations of the transition planning meetings. At the beginning of the series of meetings, all participants should agree the terms of reference, which need to be particular to each young person. At the beginning of the process, each participant should have the opportunity to express their anticipated desired outcomes and how those outcomes should be achieved. This would add clarity of purpose, mutual understanding and respect from the outset.

A young person with PMLD will have little or no previous experience of attending meetings so will need, therefore, to have the prior opportunity to enact some form of role-play of a meeting. The transition meetings need to be organised so that they are accessible and comfortable for the young person: they should take place in a venue where the young person feels comfortable and relaxed, and be structured to provide the maximum opportunity for the young person to feel included. The young person should feel that they are the centre of attention for the duration of the meeting and should be accompanied by their personal transition advocate.

Throughout the transition process, the young people must be in control as much as possible. In order to achieve this, each young person should have a personal digital passport (PAMIS, 2020), in the form of a personal iPad or similar device, that visually demonstrates important features of their care and communication. It could be updated as required throughout the transition process by a specifically designated person in partnership with the young person and would provide a means whereby the young person could communicate how best their personal needs can be met and examples of their idiosyncratic communication.

The personal statement would be developed in collaboration with the communication partner who had been sharing the intensive interaction sessions with the young person. It would include visual demonstrations of those things and activities that are important to the young person. These can be modified throughout the transition planning process. It would be a means for the young person to present themselves at the transition

planning meeting. At the beginning of each meeting, the young person's updated personal statement should be played to reflect the changes and developments in the young person in the course of the series of meetings. These must be acknowledged and respected within each meeting. During the regular interactive sessions, the young person will have the opportunity to share more of themselves.

The meeting will need to be recorded in a manner that suits the requirements of all those present and taking part in the transition process. The method could be designed by individual schools and may take the form of an audio-visual record which would aid the young person's recall of the previous meeting. This could then be transcribed into the format required by the statutory authorities. The crucial element is that the young person is at the centre of the meetings and other significant people fully participate in the process.

6.9.4 To View and Note Each Young Person's Contribution to Class, School and Wider Community Activity

Throughout the young person's time at school, they will be developing and demonstrating their contribution to the class and school community, including attributes such as developing and sustaining deep friendships, humour, determination, popularity with peers and staff and their ability to draw people to them. Young people with PMLD are part of a family and broader networks and these need to be acknowledged, noted and developed. For example, Harry had a close friendship with his grandmother. Could this type of relationship be developed with similar people in the community? The implementation of a school ethos that endeavours to enable and develop participation in all activities will require everyone in the school community to be alert to the young people's attributes as noted above. In a school setting, this could be effected by re-examining the annual review to incorporate the community attributes demonstrated by the young people. It will require a shift in attitude for many people who support young people with PMLD in a variety of roles, who will need to develop a positive, pro-active approach to these young people (Mercieca, 2013; Simmons & Watson, 2014). I have worked with young people with PMLD who have been involved in providing training to hospital staff about patients with PMLD and similar disabilities.

This was a way for them to contribute to the community. Contributing to the community may simply take the form of raising awareness of young people with PMLD in the community in which they live. A young man with whom I used to work, who has PMLD and very challenging behaviour, lives quite close to me. I often see him out walking with a carer, being himself, shouting out, sitting down and refusing to move from time to time. The local community accepts him and acknowledges him as a member of their community. In this way, he is contributing to the inclusiveness of the community.

It must be acknowledged that young people with PMLD will always need care and support because they have lifelong disabilities and medical conditions. This should not, however, prevent them from contributing to their communities. A change in attitude is needed to see young people with PMLD as having the potential to contribute rather than always being seen as the recipients of care and support. It will require imagination and reflection on the part of those who know them well. Suggestions regarding their individual contribution could be included in each young person's visual personal statement.

6.9.5 Influencing Policy

A school leader is in a position to advocate for and influence wider policy and community attitudes towards young people with PMLD. The practice developed in one school can be shared with a wider audience through professional networks and presentations at conferences and similar events. A school leader is in a position to challenge and provide feedback to local and national policy-makers; however, it is important to be able to offer alternatives or potential solutions to the elements being challenged. The practice developed in a school can be the source of informed discussion with policy-makers and implementers, providing a clear sense of direction to any discussion.

6.9.6 Conclusion of Recommendations

The recommendations are discussed from the perspective of school leadership because that is where the research project began. This provides a clear location for the

recommendations and how they may be implemented. This project has raised many issues that require attention. In many ways, it is just the beginning of a much wider research requirement, a need to sit alongside young people with PMLD to listen to them, through a deep appreciation and understanding of their idiosyncratic communication and complex difficulties. There is a need to work to articulate that knowledge honestly and respectfully on the behalf of individual young people with PMLD but also young people with PMLD as a wider group within our society.

ABBREVIATIONS

BERA	British Educational Research Association
BILD	British Institute of Learning Disability
DOB	Date of Birth
DT	Design Technology
EACH	East Anglian Children's Hospice
EHCP	Education, Health and Care Plan
IEP	Individual Education Plan
ILS	Independent Living Skills
IT	Information Technology
KS	Key Stage
LA	Local Authority
LSA	Learning Support Assistant
NHS	National Health Service
OT	Occupational Therapist
PAMIS	Promoting A More Inclusive Society
PATH	Planning Alternative Tomorrows with Hope
PE	Physical Education
PECS	Picture Exchange Communication System
P levels	Performance targets
PMLD	Profound and Multiple Learning Disabilities
PSHE	Personal, Social and Health Education
QCA	Quality and Curriculum Authority
RE	Religious Education
SALT	Speech and Language Therapy
SEN	Special Educational Needs
SEND	Special Needs and Disability
SLD	Severe Learning Difficulties
STER	Short Term Enablement Plan
TA	Teaching Assistant
T	Teacher
UN	United Nations

GLOSSARY

1. Annual Review Reports: All pupils with an EHCP must be given a detailed annual report of their educational progress. This contributes to the review of the EHCP.

2. ASD: Autistic spectrum disorder. Many pupils in specialist provision display aspects of behaviour that may be on the autistic spectrum.

3. Break down tasks into small steps: Pupils with learning difficulties may have difficulty understanding and assimilating tasks. Therefore, tasks are broken down into very simple basic steps that lead eventually to the understanding of a more complex task. For example, in washing hands, the first step may be for the pupil to hold their hands under the running water with support from a member of staff. The pupil then holds their hand under the tap independently. Then, with support, they use soap and so the task unfolds and is slowly assimilated.

4. Cerebral Palsy: A condition caused by an injury such as oxygen starvation before, during or immediately after birth. It manifests in various ways: physical difficulty with muscle movements, speech difficulties, epileptic seizures and possible learning difficulties.

5. Children and Families Act 2014: This was designed to ensure that all children can access support and provision. The Act included a new Code of Practice for Special Educational Needs.

6. Circle Time: The class sits in a circle, including staff and pupils. This is a time for sharing within the group, usually in an activity that involves everyone, and promotes listening, communication and attention skills.

7. College Link Programme: This usually take place in Year 11 when students have the opportunity, usually as a group, to visit and spend time in a variety of local post-16 provisions. The young people are usually accompanied on each visit by school staff

8. Communication Skills: Communication skills are normally understood to mean the ability to share, and convey effectively, ideas and feelings. The young people in this project have significant difficulty with communication, meaning they may lack comprehension, fluency, listening skills and the use of body and facial expression. As a result, young people may experience failure when trying to communicate and exclusion from events, activities and relationships.

9. Communication iPad: Various programmes can be loaded on to an iPad to support communication, including symbols and synthesized voice communication. This is a constantly developing field of communication technology.

10. Constant Prompts: Young people with PMLD often require constant encouragement and reminders. These may be verbal reminders and repetitions or they may be physical, by gently guiding movement.

11. Continuing Care Assessment: The NHS provides health care packages for people who have significant ongoing healthcare needs. These needs are assessed within an agreed framework. Young people with PMLD may be entitled to an NHS care package for any of the following reasons: mobility problems, long-term medical conditions, physical/mental disabilities, behavioural/cognitive disorders and complex medical conditions.

12. Complex chronic health issues: Young people with PMLD require attention from multiple health and care providers. Each has a unique combination of disabilities and functional limitations.

13. Dell Communication Aid: A specific type of electronic communication aid.

14. Downs Syndrome: A genetic disorder caused by an additional copy of chromosome 21. It is associated with delay in growth, specific facial characteristics and cognitive disabilities.

15. Echolalia: Repetition of vocalisations made by another person, made with little to no meaning.

16. Epileptic Seizures: A burst of electrical impulses in the brain greater than normal limits. These may spread to other areas of the brain and be transmitted to muscles causing various forms of twitching and convulsion.

17. Fine Motor Skills: Co-ordination of small muscles in hands and fingers usually in alignment with eye coordination.

18. Gastrostomy Feeding: A tube is inserted into the abdomen to supply nutrition when a person is having difficulty feeding.

19. Gross Motor Skills: Co-ordination of the large muscles of arms, legs and torso.

20. Hemiplegic: A condition that affects one side of the body due to injury to those parts of the brain that control movement of limbs, trunk and face.

21. Higher Tariff Funding: This funding is additional to the core SEN budget. It is allocated by local authorities according to the specific needs of particular pupils.

22. IEP Targets: The Individual Education Plan sets out specific details and strategies to support individual pupils' learning.

23. Independent Living: Based upon equal opportunities, self -determination and respect to enable disabled people to live in the community with support if necessary.

24. Individual Outcomes: Outcomes that are specific to one person.

25. Informed Choices: To make an informed choice, people need information that is accessible to them, and support to think the choice through and to understand the possible consequences of the choice they make.

26. Life Skills: The term includes a wide range of activity including domestic skills, social skills, hobbies, interests, community skills and any other skills that may enhance the quality of life.

27. Management of Behaviour: To enable people to choose socially acceptable, fulfilling and productive behaviours for the individual.

28. Music Therapy: This is a psychological clinical intervention delivered by a registered music therapist. It helps those whose lives have been affected by injury, illness or disability by supporting their psychological, emotional, cognitive, physical, communication and social needs.

29. Non-Verbal Communication: Communication without the spoken word, instead using gesture, facial expression, body language plus any other social and environmental cues.

30. Objects of Reference: an object that is systematically used to represent an item, activity, place or person.

31. Objectives of Statement: A statement of SEN was applicable before the 2014 Children and Families Act. The objectives of the statement were to provide a positive learning environment for students with SEN to facilitate their learning.

32. Oxygen at Night: Nocturnal supplements of oxygen can be used to supplement low oxygen levels in the blood.

33. P Levels: Performance attainment targets and descriptors for pupils age 5–16 with SEN who work below standard national curriculum levels. They could be used in schools until July 2018.

34. Personal Budget: An agreed amount of money allocated to an individual by the local authority following an assessment of that individual's care and support needs.

35. Personal Care: Assistance with dressing, feeding, washing, toileting and general personal hygiene.

36. Person-Centred: to put the person at the centre, considering their desires and seeing them as a unique individual.

37. Picture Exchange System (PECS): A system of chaining, prompting, cueing and modelling the exchange of a picture or symbol for a desired object.

38. Poor muscle control: Can be known as hypotonia. It is usually apparent at birth, when an infant is not able to keep their knees and elbows bent. The child may struggle with feeding and motor skills as they grow.

39. Pressure Sores: Injuries to the skin and underlying tissue caused by prolonged pressure to the skin. This can affect people who spend prolonged periods in a wheelchair.

40. Pupil Premium: Additional funding to state-funded schools in England, designated to help disadvantaged pupils of all abilities.

41. Self-Help Skills: The development of independent feeding, dressing, hygiene and simple domestic tasks such as setting the table, tidying a room, etc.

42. Sensology: an enjoyable and positive way to awaken and develop the individual's sensory systems.

43. Sensory-Based Course: Courses that are delivered through a sensory approach, using the five senses to stimulate and encourage learning in the designated area.

44. Sensory Cooking Experiences: To make cooking a more sensory learning experience through the use of ingredients and foods that have contrasting smells or textures and of foods that change texture, for example, cake mixture to a baked cake.

45. Sensory Impairment: When any of the senses do not function normally, for example, wearing glasses.

46. Social Care Needs: Support with daily activities such as feeding, dressing, washing, toileting and mobility.

47. Social Skills: Skills used to communicate and interact with another person verbally or non-verbally.

48. Specialist Learning Support Assistant: Supports pupils with complex medical conditions to enable inclusion in mainstream and special schools. They also provide educational support in the home when a pupil is unable to attend school due to medical conditions.

49 Splints: A device used to support or immobilise a limb. It can be used in multiple situations, to temporarily restrict the movement of joints and limbs. It can also be used to support joints and limbs during activity.

50. Statement of SEN: Sets out a child's needs and the help they should receive and is reviewed annually. The statement was replaced by the EHCP following the Children and Families Act 2014.

51. Switches to make choices: Switches are electronic pieces of equipment used to enable students with a wide range of disabilities to make choices. The switches can be powered through a computer programme or battery or be mains-operated. The individual switch is activated by contact with purposeful movement by the student, such as touch, blink, blowing. The student needs to learn to use the switch and understand the relationship between cause and effect.

52. Symbols: In the context of people with learning difficulties, a symbol is a sign that signifies or represents an object, a relationship, or an idea.

53. Tac Pac: A sensory communication resource using touch and music to align the senses and develop communication.

54. Taste Resources: Exploring the sense of taste with a variety of food-based ingredients and contrasting tastes of bitter, sweet, hot, cold etc.

55. Tracheostomy: An opening made in front of the neck to enable the insertion of a tube into the windpipe to assist breathing.

56. Transition Planning Meeting: All young people in Year 9 and above who have an EHCP should have an annual transition planning meeting to prepare for the transition to the post-school placement. The meeting should include the young person, his/her parents and all the professionals involved with the young person. The school that the young person attends organises the meeting.

57. Vocalisation: Sounds produced by the voice, an act of expressing feelings, ideas and desires.

58. Wedge: a specially designed and shaped piece of equipment that a young person may lie over to be more comfortable. The position often facilitates greater opportunity to engage with particular activities.

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